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The forgotten victim: an in-depth look and an overall assessment of Alzheimer's caregivers' needs, struggles, and satisfactions

Angela Lynn Smith
Iowa State University

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The forgotten victim: An in-depth look and an overall assessment of Alzheimer's caregivers' needs, struggles, and satisfactions

by

Angela Lynn Smith

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UMI
300 North Zeeb Road
Ann Arbor, MI 48103

Graduate College
Iowa State University

This is to certify that the Doctoral dissertation of

Angela Lynn Smith

Has met the dissertation requirements of Iowa State University

Signature was redacted for privacy.

Committee Member

Signature was redacted for privacy.

Committee Member

Signature was redacted for privacy.

Committee Member

Signature was redacted for privacy.

Committee Member

Signature was redacted for privacy.

Major Professor

Signature was redacted for privacy.

For the Major Program

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For the Graduate College

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ABSTRACT

Alzheimer's disease is currently the fourth leading cause of death in adults (Alzheimer's Disease, 1994). Approximately four million Americans have Alzheimer's Disease, and an amazing 14 million are projected to have the disease by the middle of the next century unless a cure is found (Alzheimer's Disease, 1994; Iowa Department of Elder Affairs, 1992). Nearly 40 primary caregivers offered life stories of how Alzheimer's has impacted their lives. Spiritual, legal, financial, home modification, medical, and emotional needs were discussed by caregivers. Twelve in-depth interviews were conducted to gain greater insight into how practitioners in diverse fields can best help primary caregivers. A questionnaire was developed from the interviews to seek commonalties among caregivers on a greater scale. Primary caregivers stated needs, struggles, and satisfactions in caring for persons with Alzheimer's and suggested what would help them most in providing the best possible care. Results from this study provide 1) a brief history and definition of Alzheimer's Disease, 2) stages of caregiving in relation to the patient's status, 3) how Alzheimer's impacts primary caregivers needs, struggles, satisfactions, and meaning-making, and 4) how practitioners from diverse fields can best help primary caregivers.

CHAPTER 1

INTRODUCTION

'When you are joyous, look deep into your heart and you shall find it is only that which has given you sorrow that is giving you joy. When you are sorrowful, look again in your heart, and you shall see that in truth you are weeping for that which has been your delight.'

Kahlil Gibran

Efforts taken to prolong the earlier stages and minimize the more devastating stages of Alzheimer's disease have been limited by focusing more on the needs of the patient suffering directly with Alzheimer's disease and somewhat less than those who suffer indirectly: the caregiver. Based on both quantitative and qualitative paradigms from interview and survey methods and results, the following project attempted to develop an understanding of the needs, struggles, and satisfactions of Alzheimer's caregivers. This information will then be provided to physicians and therapists who can build practices to offer necessary information to both patient and caregiver at time of diagnoses and follow-up visits.

Alzheimer's disease is currently the fourth leading cause of death in adults (Alzheimer's Disease, 1994c). Approximately 4 million Americans have Alzheimer's disease, and 14 million Americans are projected to have Alzheimer's by the middle of the next century unless a cure is found (Alzheimer's Disease, 1994b; Iowa Department of Elder Affairs, 1992). The Alzheimer's Association (Alzheimer's Disease, 1994d) has described the disease as a progressive, degenerative disease that attacks the brain and leads to impaired memory, thinking, and behavior. The disease can progress over a span of 3 to 20 years, beginning with no noticeable difficulties, with the possibility of a number of illnesses leading

to death. A plethora of research already has been completed on Alzheimer's patients and the paths that they follow.

Unfortunately, much is left to learn about the disease, especially how it affects the needs, struggles, and satisfactions of the primary caregivers. Some researchers have found that caregivers of Alzheimer's victims have more unmet needs than do caregivers of other diseases (Straw, O'Bryant, & Meddaugh, 1991). With this in mind, little is known about whether caregivers' financial, legal, medical, housing, emotional, and spiritual needs are being met either by their spouse, family members, or others outside of the nuclear family.

Not only is this information itself important; but how the information is collected is of equal importance. Caring for a loved one, no matter if the individual is ill or not, is a very personal experience. It is unlikely that such a personal experience can be captured solely through the use of structured interviews, surveys or questionnaires.

Many researchers have selected to utilize specified surveys and questionnaires with limited choices when collecting data on caregiving (Acton & Miller, 1996; Fritz, Farver, Kass, & Hart, 1997; Orbell, Hopkins, & Gillies, 1993). However, it is important to understand the effects of Alzheimer's disease on caregivers and to assess the burden and grief that accompany caring for a loved one. Therefore, this researcher will be dedicated to meeting the needs of caregivers and understanding donated information to better assist primary caregivers.

Given the primary nature of past studies, aspects of qualitative methodology will be utilized to better understand caregiver's and patients' needs, concerns, and satisfactions. This researcher will conduct an investigation through a qualitative or phenomenological perspective and attempt to acquire an understanding of certain events, actions, or interactions

in their naturally occurring environments from the participant's viewpoint (Moon, Dillon, Sprenkle, 1990). The purpose of this study is to fill the need for understanding caregivers' needs, struggles, and satisfactions, and the use of qualitative methods in understanding caregivers.

The following project will attempt to develop a process for better understanding the needs, struggles, and satisfactions of Alzheimer's caregivers. This will involve an investigation of the many facets of the informant's experience as a caregiver. This information then will be provided to physicians and therapists who can build practices to offer necessary information to both patient and caregiver at time of diagnoses and follow-up visits. This information will be collected through in-depth face to face interviews and a questionnaire containing both closed and open-ended questions. The following paragraphs describe the purpose, the pertinent interview questions, delimitations, and significance of study.

Purpose

The purpose of this study is to learn more about the process involved in living as a primary caregiver of an Alzheimer's patient. In addition, the goal is to learn more about the needs of caregivers, the struggles faced, and the satisfactions experienced by caregivers. This information will be gathered through ethnographic interviews with a number of primary caregivers of Alzheimer's patients. Due to the initial exploratory nature of this study, qualitative methodologies will be used to develop a grounded theory of caregiver's experience. Following the establishment of a grounded theory using qualitative methodologies, quantitative methods will be used to confirm results of the interviews and provide data generalizable to similar samples of Alzheimer's caregivers.

The following grand tour, mini tour, and sub-questions will be utilized in the qualitative portion of this research. The interview process will provide flexibility and may not follow the questions in order. However, all topics will be covered at some point during each interview.

Grand Tour Question

What has it been like for you to be a primary caregiver of an Alzheimer's patient?

Mini Tour Questions

What has it been like living with an Alzheimer's patient?

What has it been like to live as a primary caregiver for an Alzheimer's patient?

Sub-Questions

Which of your needs do you feel have not been met through your process as a primary

caregiver?

Which of your needs do you feel have been met through your process as a primary caregiver?

Describe any changes in your style of living since becoming a primary caregiver.

Describe any changes in your occupation since becoming a primary caregiver.

What skills or assistance would help you most in your life as a primary caregiver?

Did you experience any differences after the diagnoses in 1) finances, 2) legal matters, 3) medical assistance, 4) housing situation, 5) emotional support (i.e., family, non-family) 6) spirituality/religion?

Delimitations

Delimitations are processes of how the broad goals of the study can be narrowed in scope (Creswell, 1994). The broad scope of this study is to investigate the process of living as an Alzheimer's primary caregiver. Due to the myriad of possible answers, sub-questions are used to narrow the overarching question to very specific 'bite size portions.' These more specific questions address the basic needs, struggles, and satisfactions that have or have not been met throughout the caregiving process.

Significance of Study

This study is an attempt to develop a grounded theory of the needs, struggles, and satisfactions of Alzheimer's caregivers. The goal of this study is to promote a safe home environment with adequate need fulfillment for both patient and caregiver throughout the Alzheimer's disease process. Based on both quantitative and qualitative data, the project will offer information from primary caregivers that can then be offered to individuals who presently care for a close relative diagnosed with Alzheimer's disease. This information will also be provided to practitioners working in diverse fields who can offer assistance to patients and caregivers living with Alzheimer's.

CHAPTER II

LITERATURE REVIEW

Past Research

The History of Alzheimer's

Alzheimer's was first identified in 1906 by a German neurologist, Alois Alzheimer. Alois was seeing a 51 year old female client who appeared to be experiencing problems with her memory and seemed depressed and disoriented. Alzheimer observed his client's condition deteriorate until death. After death, an autopsy was performed on the client's brain. This autopsy revealed cortical atrophy and neurofibrillary tangles present in the cerebral cortex.

More than 90 years later, the cause of these neurofibrillary tangles are still under investigation. In fact, several theories exist on why some people more than others develop an excess of neruofibrillary tangles and neuritic plaques in the brain. These theories include the Aluminum Theory, Viral Theory, Genetic/Heredity Theory, Immune-System Theory.

To begin, the Aluminum Theory states that aluminum levels in the brain naturally increase as individuals age. However, Thienhaus, Hartford, Skelly, and Bosmann (1985) found abnormally high levels of aluminum in people who had been diagnosed with dementia. Since the 1980's, research has suggested that aluminum in high amounts may play some factor in Alzheimer's; however, it does not seem to be the cause of the disease.

The Viral Theory as researched by Prusiner (1984) suggests that a virus-like agent may be the root cause of Alzheimer's. After all, diseases such as Creutzfelt-Jacob and Kuru, which reportedly induce dementia are caused by these virus-like agents. While this theory is possible many researchers have suggested that the viral theory is not likely. However, some

researchers suggest that the combination of viral and genetic factors is likely to be the cause of Alzheimer's.

Genetics may contribute to Alzheimer's in more than one way. Genetics is an important factor when assessing early-onset Alzheimer's and perhaps less significant when analyzing later-onset of the disease. Genetics are also a significant component when understanding Down's Syndrome and the likelihood of Alzheimer's.

The role of genetics seems to be especially significant for those under the age of 65 who are living with Alzheimer's. According to the researchers (Schellenberg & Tanzi, 1995), autosomal dominant amyloid precursor protein (APP) chromosome 21 is linked to early-onset Alzheimer's Disease. Unfortunately, there is a low accountability of the gene to the Alzheimer's outcome (2-3%).

A second gene said to be associated with early-onset Alzheimer's is the pre-senilin 1 gene, identified on chromosome 14. Researchers speculate that about half of the cases of multi-generational familial Alzheimer's disease may be attributed to mutations in this gene (Tanzi, 1999). Another gene, pre-senilin 2, is very similar to the pre-senilin 1 gene and has been said to account for up to 20% of the familial Alzheimer's cases.

While replication of results on chromosome 21 and 14 are limited, a genetic factor does seem appropriate for those under the age of 65. Chromosomes 21 and 14 are typically at fault only in those diagnosed with early-onset Alzheimer's, with no apparent connection to the later-onset.

Researchers have suggested that the e2, e3, and e4 version of the Apolipoprotein E (APOE) gene on chromosome 19 are much more common in people with late-onset Alzheimer's (Tanzi, 1999). This research has been confirmed by more than two dozen teams

around the world, with no contradictory evidence. An important distinction is made about the APOE gene. This gene is not defined as a disease gene, that is, not everyone who carries the APOE gene will develop Alzheimer's and not everyone with Alzheimer's carries the APOE gene.

From information offered in the DSM-IV it appears that individuals born with Down's Syndrome are likely to show features of Alzheimer's by middle age, most by age 40. Chromosome 21 seems to play a significant part in those with Down's Syndrome, individuals with Down's have extra copies of chromosome 21. This genetic defect seems to promote the formation of protein substances that are abnormally deposited in the brains of Alzheimer's patients.

The Immune-System Theory expands upon the immune system of the body and the reaction to infection. Researchers who support this theory found that the proteins that fight infection in the body are abnormally low in individuals with Alzheimer's disease. Others believe that cells that are typically helpful to the body become jumbled and invade good cells instead of bad cells.

Alzheimer's Disease

Alzheimer's disease is a collection of symptoms that are characteristic of a syndrome known as dementia (Gruetzner, 1992). According to Gruetzner (1992), dementia indicates a loss or impairment of a person's abilities to use his mind. Alzheimer's is just one of many types of dementia. However, Alzheimer's is the most common type of dementia.

Approximately 5% of the population is affected by Alzheimer's disease before the age of 65 (Merrill, 1991). In addition, 10% of people age 65-84 are affected by Alzheimer's disease, and this percentage rises to 47.2% for those age 85 or older (Alzheimer's Disease,

1994b). Alzheimer's disease has been defined as 'insidious, characterized by irreversible memory impairment, deterioration in general intellectual ability, personality disorganization, and impairment in the ability to perform self-care related tasks' (Chappell & Penning, 1996, p. 57). Alzheimer's disease seems to be the most frequent cause of irreversible dementia in adults.

The factors or attributes possessed by an individual with Alzheimer's are not typically consistent from one individual to the next. Just as all individuals are unique, so are the attributes possessed by an Alzheimer's patient. Individuals suffering with Alzheimer's disease tend to experience the following behaviors (Alzheimer's Disease, 1996): 1) agitation and restless behaviors, 2) dependent and clinging behaviors, 3) repetitive and ritualistic behaviors, 4) mistakes in recognition and perception, 5) demanding and aggressive behaviors, and 6) exaggerated emotional responses. In addition, several formulations of Alzheimer's stages, progressing in severity, have been offered in the research literature (Gwyther, 1985; Reisberg, Ferris, de Leon, & Crook, 1982). The stages offered by Gwyther, (1985) seem detailed, yet not as complicated as other researchers who have described up to seventeen stages in the disease process (Figure 1).

The early, middle, and late stages of Alzheimer's are uniquely clustered in Figure 1. Each stage is characterized with behavioral and mental changes that affect many Alzheimer's patients. The changes that are outlined in figure one may not affect all patients in the same way or in the same order. That is, some patients may never lose their ability to communicate while another patient may experience a loss described in the middle stage in the earlier stage of the disease process.

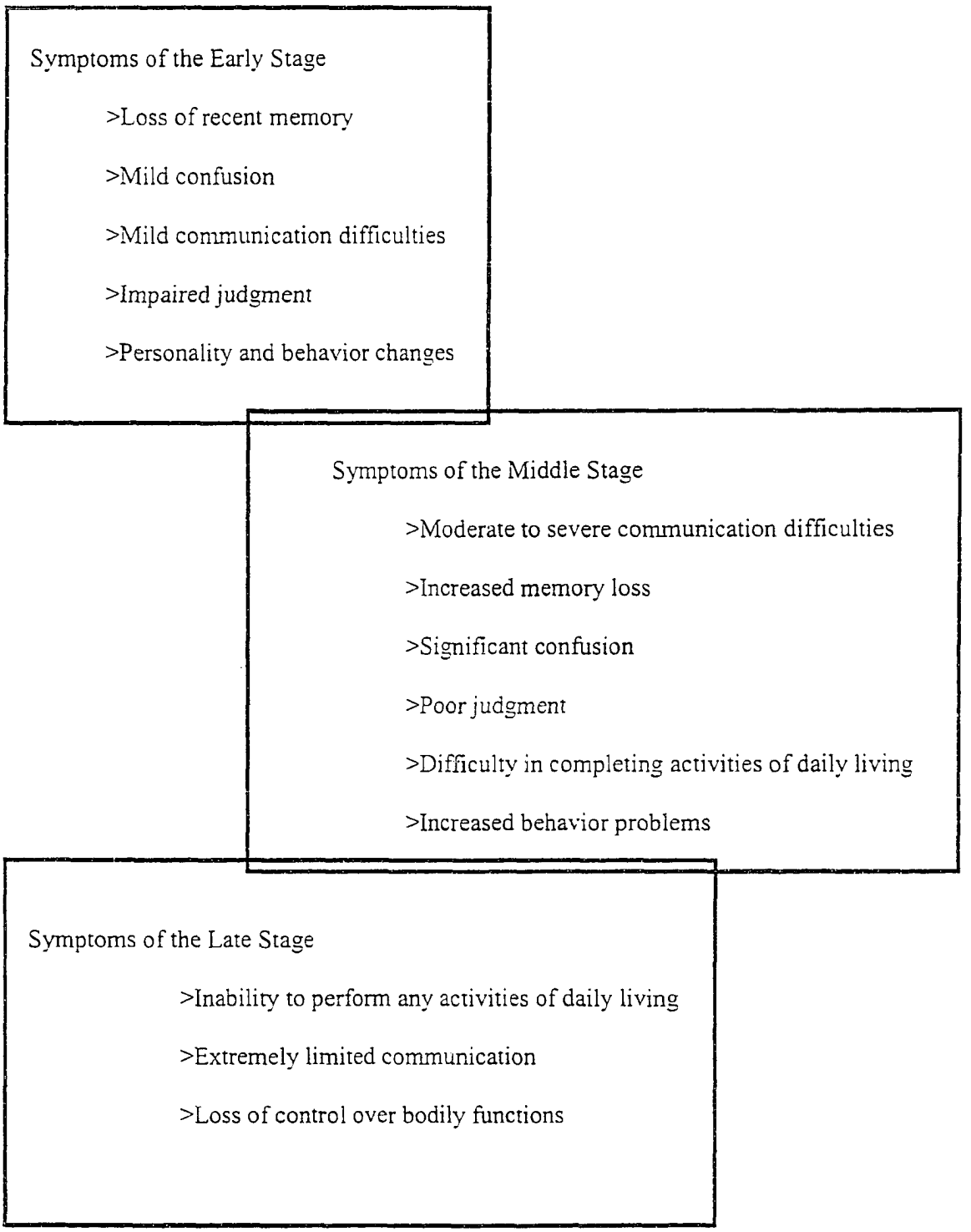

Figure 1. Symptoms of Early, Middle, and Late Stages of Alzheimer's Disease

Not only do the attributes and stages differ among Alzheimer's patients, so does the length of time the patient suffers from the disease. It has been suggested from the Alzheimer's Association (Alzheimer's Disease, 1990) that after the onset of symptoms, the life span for those with Alzheimer's can range from 3 to 20 years. Unfortunately, the patient is not the only one suffering from this devastating disease; the primary caregivers are suffering, too.

Alzheimer's Caregivers

An enormous amount of research has focused on those suffering directly from Alzheimer's disease; however, there are a number of individuals, specifically primary caregivers, who suffer indirectly. Gold, Franz, Reis, and Senneiville (1994) found that 67% of the 131 caregivers were the spouse of the demented patient. A similar study by Harper and Lund (1990) indicated that 216 out of 270 caregivers in their study were spouses of the dementia patient.

Primary caregivers are also likely to be children of the Alzheimer's patients. Female adult children are more likely than sons or sons-in law to care for parents suffering with Alzheimer's. Women are especially more likely to care for the daily needs including bathing, feeding, clothing, and transportation. Sons, on the other hand, are usually more likely to provide financial assistance and legal support for their parent.

The Family Caregivers Alliance (1990-1992) found that 76% of a sample of 4,868 caregivers were female, with a mean age of 59. These researchers found that 75% of these caregivers lived with the patient, 32% work in addition to being a caregiver, and 18% decided to quit work to be a caregiver. The average amount of time dedicated to caregiving per week was 93.3 hours. From these results, it is not surprising that many needs of the

caregiver may not be met adequately. The following sections will provide past literature in components that may affect the lives of caregivers.

Financial Needs of Caregiving

An amount of $47,000 in total costs may be necessary to pay for the formal and informal care for an Alzheimer's patient (Max, 1993). In fact, some researchers suggest that the average lifetime cost per patient may be closer to $174,000 (Alzheimer's Disease, 1994b; Iowa Department of Elder Affairs, 1992). With these dollar amounts, it is not surprising that Alzheimer's disease is the third most expensive disease in the United States after heart disease and cancer (Alzheimer's Disease, 1994b; Iowa Department of Elder Affairs, 1992).

In response to the costs that accompany caring for an Alzheimer's patient, financial assistance may not only be desirable, it may be a necessity. Caregivers may question aspects of their finances including adequate bank accounts, safety deposits, insurance, bonds, and retirement benefits. Unfortunately primary caregivers may get caught up in outstanding credit card bills, debts, and loans.

An additional financial factor impacting the lives of Alzheimer's patients and their families is the amount of assistance from insurance and Medicaid coverage. In some cities and towns Alzheimer's may be regarded as a psychiatric condition and therefore, may not meet the medical requirements that make the individual eligible for long-term care. Insurance coverage may also be complicated due to the uncertainty of the diagnosis, as Alzheimer's cannot currently be diagnosed except by autopsy.

Medicaid is an extremely confusing system to understand, as the rules change frequently and vary from state to state. Medicaid offers assistance to low income elderly, and eligibility for home care and day care is limited. Unfortunately, there is not a national

resource that assists middle-class families with the costs of home or day care. Therefore, families of all economic classes in need of assistance are subjected to endless searches for the proper help in caring for the Alzheimer's patient.

Legal Needs of Caregiving

Caregivers not only are likely to face financial difficulties; it is likely that legal battles also may occur through a lack of or changes in advance directives, living will, power of attorney, and/or life-sustaining procedures. Advance directives are documents that allow a patient to make decisions about his/her medical care in reference to their future condition(s) (Brenton & Larson, 1995). Advance directives are of great significance especially when suffering from a disease such as Alzheimer's. A competent adult (one who has the capacity to understand) is needed in completing an advance directive; therefore, an individual diagnosed with Alzheimer's would have to decide on his/her medical care while still in the earlier stages of the disease.

If an advance directive was not established by the patient, a durable power of attorney is another document that could be utilized. A durable power of attorney is a legal document that allows the patient to choose someone as an agent to make health decisions whenever the patient cannot, due to the inability to think or reason (Brenton & Larson, 1995). As mentioned previously, the legal issues can be very traumatic to a caregiver who is required to make extreme decisions for another individual. Fortunately, the person who has power of attorney is making these decisions through either written or verbal directions given by the patient.

A third type of document is a living will, sometimes also known as life-sustaining procedures, a document directing a physician to withhold or withdraw certain treatments that

could prolong the dying process (Brenton & Larson, 1995). An important point to remember is that sometimes individuals change their mind, and changes may be necessary on one or all of these documents.

Strangely enough, changes or cancellations can be made on these documents at any time, despite the individual's physical condition. These changes or cancellations have the possibility of affecting several individuals including the caregivers, relatives, and even doctors. It is possible that these individuals may not agree with the directives that were stated by the patient. In these cases unforeseeable situations may arise. For example, if a doctor is unwilling to follow a patient's wishes, he/she may have to be referred to another doctor or possibly transported to another hospital. These changes tend to be more detrimental to the caregiver and/or relatives. Therefore, certain services may be necessary to help these individuals deal with life-sustaining or life-terminating decisions.

Medical Needs of Caregiving

Assessing the medical needs of the patient go beyond the legal aspect presented in the previous section. In fact, this section assesses the medical needs of the patient and the caregiver. To begin, it has been found that approximately 43% of caregivers rate their own health as fair to poor; in addition, 66% of caregivers show clinically significant depressive symptoms (Family Caregivers Alliance, 1990-1992). Given these statistics, a closer look should be taken at the needs of caregivers. So much time in the day is spent on the patient that the caregiver's needs are often neglected. The caregiver needs to remember him/herself as a priority and make time for meals, exercise, and quiet time each day. The caregiver is occupied otherwise with the complex medical needs of the patient.

The caregiver easily can become overwhelmed by the medical needs of the patient. The caregiver's responsibilities may include administering medications to the patient, assisting with hygiene by giving baths, or provide restroom assistance due to loss of bladder or bowel control in the patient.

Along with these stressful situations come the likelihood of more severe medical problems. As the Alzheimer's patient progresses to the later stages of the disease, problems such as falls, injuries, dehydration, and pneumonia are common. These medical problems are often left with the caregiver to deal with and require decision-making that benefits both the patient and the caregiver.

Although people with dementia can experience pain, they may not be able to tell you that they are in pain or that they have a broken bone. Falls may become more likely due to changes in the dementia patient's depth perception. The change in depth perception added to the vulnerability to fragile bones as one ages could result in a disastrous outcome.

An Alzheimer's patient may experience dehydration or malnutrition throughout the disease process. After all, individuals tend to decrease their fluid intake as they age, making dehydration a possibility. In addition, elderly tend to eat more sweet or sugar based foods because this is the last of the taste buds to diminish. Unfortunately, this combination makes it all too easy for an Alzheimer's patient to become malnourished or dehydrated.

Pneumonia is a serious problem for those suffering from Alzheimer's. In fact, pneumonia, not Alzheimer's itself is usually the cause of the death for individuals suffering with this disease. Pneumonia is most likely to affect Alzheimer's patients who frequently choke when eating or drinking or for patients who are bed ridden.

Medical needs, assessment, and risks must continuously be considered for both the typically overworked and grieving caregiver and for the Alzheimer's patient who may not have the ability to say that something is wrong. With appropriate knowledge and medical support the caregiver should be able to help herself and the patient to a healthier life.

Housing Needs of Caregiving

In caring for an Alzheimer's patient the proper home setting has to be considered. Through the earlier stages of the disease, the caregiver may be able to care for the patient in the home. However, safety modifications in the home may have to be installed; such as hand-rails throughout the home, extra locks for doors, and possibly even extra doors or gates to avoid fleeing during the patient's wandering periods.

Typically, a time comes when the caregiver no longer can care for the patient in their home. In the Family Caregivers Alliance study (1990-1992), 70% of the caregivers stated that the patient could not be left alone and 46% stated that the patient could not communicate or follow directions. With these difficulties the best choice for the caregiver and the care-receiver may be a care facility or nursing home.

Mace and Rabins (1991) have several suggestions for the caregiver when deciding on a nursing home. They suggest that the caregiver visit several care facilities and decide on one that he or she finds comfortable. The caregiver should put the patient's name on a waiting list even if the patient never needs the home. Many good nursing homes have waiting lists. Consequently, it is better to make arrangements ahead of time than to wait until the patient really needs extra care.

Mace and Rabins (1991) also established some general guidelines for evaluating nursing homes. First, these researchers suggest that the caregiver evaluate the care facility,

especially the kitchens and bathrooms checking for cleanliness and smell. Second, they recommend that the caregiver become familiar with the fees and obtain a written explanation of what the fees cover. Third, they advise the caregiver to assess whether the staff understands how to care for individuals with dementia. Fourth, it is important to determine whether the facility cares for the patient's needs in areas such as medication, food, recreation, and supervision. Some final recommendations the researchers offer, is for the caregiver to become familiar with the requirements of licensure for the facility, the rights of the patient, and the contract established for the patient.

Emotional Needs of Caregiving

In addition to the needs already mentioned, intimacy is investigated rarely by researchers when assessing caregiver/patient relationships. The Alzheimer's Association (Alzheimer's Disease, 1996) mentions that feelings of regret and loneliness may surface as caregivers tend to experience lessened intimacy and closeness with their partner. Thoughts of intimacy with a spouse are not so unusual, but thoughts of intimacy with an individual that no longer recognizes you may be more difficult to initiate. This need for intimacy may be over bearing, especially if the caregiver does not have a support system that understands the complexities of living with an Alzheimer's patient (Gallagher-Thompson & DeVries, 1994).

Support systems may be helpful in addressing some of the emotional needs of caregivers by allowing them to talk about their feelings. Some of the feelings that the caregiver may be experiencing are fear, doubt, guilt, anger, relief, grief, depression, and loneliness (Alzheimer's Disease, 1994a). The fear could result from not knowing the progression of the disease or the next action of the patient. Caregivers also may doubt if they have made the right or best decisions along the way. As with those who are forced to put a

loved one in a care facility, guilt is an emotion that can flood the caregiver. Furthermore, mixed feelings can plague the caregiver, such as feeling angry that they have had to struggle indirectly with the disease, yet relieved when death finally comes. Relief is often the emotion that emerges from the caregiver when they no longer have to see a loved one suffer.

Support groups are one way of receiving help from others. Support groups may be one component of a caregivers support system. Support groups are provided in many states through the Alzheimer's Association. However, many caregivers may find relief in joining a group that is not specifically for those who care for Alzheimer's patients. Support groups differ from group to group. Some groups may choose to have a learning or educational environment, others may wish to have time to spend with people who understand their experience, while other's, yet may have a combination of the two.

Family, friends, and neighbors may make up other components of the caregiver's support system. In a study by the Family Caregivers Alliance (1990-1992), 27% of the 4,868 caregivers stated that they received no help from family and friends. This statistic may be high because assistance is not available in their area, or the caregiver may not be aware of what types of assistance are offered. Assistance may be as close as next door. A neighbor, friend, or relative may be willing to help with housework, lawn maintenance, and grocery shopping. However, this help may not be enough, and more specific services may be needed.

More specific services include home-delivered meals, home health aids or care, housekeeping services, respite care, adult day centers, and transportation services. The needs of the care-receiver and the caregiver may be met through a team of assistance providers. Home-delivered meal programs differ on the number of meals that can be delivered per household; however, the meals are typically low in cost and very healthy. Home health aids,

housekeeping services, and transportation services may be a necessity for many caregivers. Unfortunately, most are billed at the expense of the caregiver. Respite care allows a primary caregiver to take some time off from caregiving. Respite care is usually offered at care-facilities, nursing homes, or facilities that specialize in respite care. Finally, both the caregivers and the Alzheimer's patient may benefit from adult day centers. These centers typically provide an eight-hour per day respite, including two meals for individuals who need a place to go while their loved one is at work. Most adult day centers have a nurse on staff and accept Medicaid.

Spirituality

Spirituality and religiosity it would seem are integral components to many individuals. Ninety-seven percent of the general population claims to be affiliated with some church. Specifically, 76% of people aged 65 and older identify religion as very important in their lives (McFadden, 1996). Spirituality, for purposes of this study, is the motivational and emotional cause of the human search for meaning. Religion is defined as the link between a higher power and human existence (McFadden, 1996). With such high beliefs in a higher being, one may conclude that there would be a large amount of research on spirituality and caregiving. On the contrary, little research exists on this area.

Religion and spirituality may address several needs in the lives of caregivers. Caregivers may look to the church as a source for social support. Caregivers may also turn to God and/or the church as a connection to seek guidance, relief, and peace of mind. Furthermore, through the devastation and desperation in caring for an Alzheimer's patient, caregivers who did not previously consider themselves as religious, may turn to God in search for understanding and hope.

Caregiver Stress

The categories of information just discussed are specific areas that may cause caregivers to feel stressed. On the other hand, there may be some stress that a caregiver feels that may not be so easy to describe. Stress may come from a number of sources that were hinted at in the previous sections. Because Alzheimer's is such a lengthy disease process, caregivers may experience several emotions that have a close connection to their level of stress. In fact, some researchers have suggested that caregivers of Alzheimer's have higher perceived levels of stress and significantly more mental health problems than caregivers of other diseases (Hooker, Monahan, Bowman, Frazier, & Shifren, 1998). The emotions that may coincide with feelings of stress are grief, guilt, depression, anger, and sadness.

As previously mentioned, families deal with a number of emotions through a prolonged disease process. Rabins (1984) describes this group of emotions as chronic grieving. Chronic grieving, because everyday there is the realization that a little more is gone from the individual suffering with this disease. Chronic grieving for spouses because dreams of the future must now be forgotten. Chronic grieving for adult children and grandchildren because they may not be able to share future events with their loved one. Chronic grieving because grieving starts from the time of the diagnosis and is replaced with a new kind of grieving when that loved one passes on.

Guilt may be experienced by caregivers who wonder if they have made the right decision. Guilt seems to be extremely likely around medical and housing decisions. Spouses are typically the most vulnerable group experiencing guilt when deciding on nursing home placement for the Alzheimer's patient (Grau, Teresi, and Chandler, 1993). As previously mentioned medical decisions can also bring on feelings of guilt and stress. The caregiver

may have to decide between prolonging the patient's life through feeding tubes or oxygen and death by withholding medical assistance.

Depression can be experienced for numerous reasons. Stress may be the cause of the depression or the caregiver may be so depressed that they become stressed about how to continue caring for the Alzheimer's patient. Depression may be extremely likely if a support system is not developed for the caregiver. Unfortunately, depression may appear, minimize, and reappear throughout the caregiving experience.

Anger is another emotion that can either cause an individual to become stressed or when stressed, one may become angry. After realizing what this disease means and how it can affect lives, anger may set in. Anger may result because future dreams now have to be put aside. Anger may result because being caregiver was not what you said you wanted to be when you grew up. Anger may result out of frustration and of not knowing what to do anymore.

A final emotion that may lead to stress is the feeling of sadness. Some caregivers may have to deal with the additional stress of wondering if their children may inherit this disease in the future. Three types of risk assessments for families were developed by Dr. Leonard Heston in 1985. Type I families have one individual with the onset of Alzheimer's at the age of 70 or above, with no other relatives affected by the disease. Risk for siblings or children begins at 65 with a higher risk at age 80. Type II states that onset of the illness occurs at an age younger than 70, with no other relatives affected by the disease. The risk for children and siblings begins at age 60 with a 16% risk by age 80. Type III risk is defined by the onset of the disease at an age younger than 70, and another relative is also affected by the

disease. Risk for the nuclear family begins at age 45 and for the extended family at age 65. The risk for nuclear family members at age 55 is 8%, 16% by age 65, and 28% by age 80.

Although several articles have been written on the level of stress in the lives of caregivers, few researchers discuss positive ways to alleviate stress in both caregiver and the patient. Feil (1993) conducted a study with caregivers of Alzheimer's patients that provided a positive way to assist both caregivers and patients. She suggested that by validating feelings as a caregiver and for the patient, caregiver burnout is reduced and the patient's frustration is minimized.

Financial, legal, medical, housing, emotional, and spiritual needs are very important to most all individuals, but are constant issues for a caregiver dealing with a spouse who has Alzheimer's. Unfortunately, little is known about which of these needs are not being met and which are. Therefore, the purpose of this study is to determine the needs, struggles, and satisfactions, of Alzheimer's caregivers.

Summary

Numerous journal articles in the past have been dedicated to research on Alzheimer's Disease, the sufferers of the disease, and the caregivers for those Alzheimer's patients. However, researchers have not acknowledged the needs, struggles, and satisfactions of the caregivers or offered information from another caregiver's perspective on what it is like to care for an Alzheimer's patient. In addition, most researchers utilize quantitative methods rather than qualitative methods or a combination of the two when assessing caregivers' lives.

It is not likely that personal experiences such as learning about caregivers' needs can be captured solely through the use of close-ended surveys. Although quantitative methods do have benefits such as allowing for generalizability from a particular sample to a larger

population, qualitative methods may be more beneficial in learning about specific needs of caregivers.

An enormous amount of research has focused on those suffering directly from Alzheimer's disease, however there are a number of individuals, specifically primary caregivers, who suffer indirectly from Alzheimer's disease. One major concern for caregivers is that of financial complications. Financial assistance may not only be desirable, it may be a necessity, due to the high cost of caring for an Alzheimer's patient. Caregivers are not only likely to get caught up in financial battles it is likely that legal battles may also occur through a lack of or changes in advance directives, living will, power of attorney, and/or life-sustaining procedures.

Assessing the medical needs of the patient go beyond the legal aspect. So much time in the day is spent on the patient that the caregiver is often neglected. These caregivers may not take the time to make him/herself a priority or make time for meals, exercise, and quiet time each day. In addition, when caring for an Alzheimer's patient, the proper home setting has to be considered. Unfortunately, there will most likely come a time when the caregiver can no longer care for the patient in one's home. Several recommendations need to be considered by the patients' family before deciding on an alternative form of living for the patient.

Finally, thoughts of intimacy with a spouse are not so unusual, but thoughts of intimacy with an individual that no longer recognizes you may be more difficult to initiate. This need for intimacy may be extremely difficult to deal with, especially if the caregiver does not have a support system that understands the complexities of living with an Alzheimer's patient. It is imperative that caregivers become more aware of assistance and

information about Alzheimer's through research directed in these particular topics. Furthermore, caregivers may have a sense of gain from researchers who utilize or integrate quantitative and qualitative methods.

CHAPTER III

MATERIALS AND METHODS

Qualitative Methods

Given the exploratory nature of the proposed study, qualitative methodology will be utilized initially to develop a theory, followed by the use of quantitative methods to verify the theory. Researchers conducting an investigation using a qualitative or phenomenological perspective attempt to acquire an understanding of certain events, actions, or interactions in their naturally occurring environments from the participant's viewpoint (Moon, Dillon, & Sprenkle, 1990). Therefore, attempts were made to position the researcher as a student and to maximize the informants as teachers. With this approach, the respondent rather than the researcher led the direction of the interview, revealing information most relevant to the informant. One overarching question was posed by the researcher to allow the respondent flexibility and subjectivity in how he or she wished to respond.

Knowledge that is gained using qualitative methodology is often defined as interpretive research (Creswell, 1994); because multiple realities exist within a particular setting (i.e., the researcher and the respondent) including biases, values, and expectations. These multiple realities allow for exploration to become divergent rather than convergent as more is learned (Guba & Lincoln, 1981) and as themes, new concepts, and insights emanate from the respondent (Lincoln & Guba, 1985). This focus on multiple realities incorporates an important point of view, that of the researcher.

The researcher is the primary instrument when he/she is using qualitative methods. Unlike quantitative surveys or questionnaires, researchers using qualitative methods are able to interact with the respondent and therefore have the capability to evolve their line of

questioning as the study progresses. Information gathered during the ethnographic interviews may be overlooked or missed in a quantitative questionnaire because the questionnaire may not reflect the lived experience of the informant. Without first completing an interview, the questionnaire could not be based on a theory grounded in the experience of the informants.

Role of the Researcher

I will be the primary instrument during the qualitative portion of the study. Therefore, it is important for me to describe myself and express my biases. For 2 years I have volunteered my time and assistance at a health care facility for elderly persons that provides shelter and care for Alzheimer's patients. Through my work with these individuals I have had the opportunity to speak with many family members. During these discussions, I have heard some of the family members speak with certainty and reassurance, while others have seemed discouraged or disappointed. The feelings these individuals expressed caused me to ponder whether the needs of the caregivers or family members are being met. These are the individuals who had provided services for the Alzheimer's patient prior to nursing home placement. I began to ask myself, who is looking out for the caregivers?

There are a number of questions that I am curious about. I am eager to learn more about caregivers, especially about Alzheimer's caregivers. I am interested in these caregivers because I am in direct contact with family members who are suffering with Alzheimer's disease. I understand the significance of working with caregivers' dealing with all diseases; however, I believe that there is a unique challenge to caring for someone who is losing mental rather than physical capabilities. In addition, I am interested specifically in Alzheimer's because of the typical duration of the disease (up to 20 years). I question how a caregiver could maintain good health and a healthy lifestyle for such a long time. These

questions convinced me that more research would be helpful in understanding and supporting caregivers.

Informants

The informants in the first part of this study included interviews with individuals who have been full-time caregivers of Alzheimer's patients within the year of the interview. The researcher utilized opportunistic sampling, including individuals from Alzheimer's support groups, adult day centers, and those learned about by word of mouth. After potential participants were identified, the researcher invited individuals to share their experience as an Alzheimer's caregiver during an in-depth interview. Before being invited, caregivers were told about the researcher's desire to learn about caregiving and that each story would allow the researcher to learn the personal triumphs and tribulations of caring for an Alzheimer's patient.

The sample for this portion of the study included twelve primary caregivers of Alzheimer's patients. Six of the caregivers volunteered to participate in the study at Alzheimer's support groups, three volunteered through adult day centers, and three individuals were found by word of mouth and accepted the invitation to participate in the study.

Primary caregivers, as opposed to secondary caregivers, were invited to participate in this research, as primary caregivers are more likely than secondary caregivers to live with the patient. In addition, primary caregivers tend to be a relative or very close friend and are able to express the differences in their own emotions prior to the Alzheimer's onset and throughout the disease process.

Caregivers of Alzheimer's patients were selected as opposed to caregivers of other diseases because of the magnitude of mental decline that must be dealt with. While caregiving for all loved ones and all diseases is an overwhelming challenge, those caring for an Alzheimer's patient appear to have an extremely different challenge. The challenge goes beyond the daily care to include a lack of communication when the Alzheimer's patient needs something, in addition to the patient's aggression, agitation, repetition, and wandering, and the loss of an intimate connection.

Measure

The measure for the qualitative portion of this study included a grand tour question, mini-tour questions, and sub-questions related to caregiving for an Alzheimer's patient. The grand tour question was very broad and open to allow the caregiver the space to provide information that he or she deemed most important. Specific sub-questions were asked later if they were not covered already in the information provided by the caregiver when answering the grand tour question.

Grand Tour Question

What has it been like for you to be a primary caregiver of an Alzheimer's patient?

Mini Tour Questions

What has it been like living with an Alzheimer's patient?

What has it been like to live as a primary caregiver for an Alzheimer's patient?

Sub-Questions

Which of your needs do you feel have not been met through your process as a primary caregiver?

Which of your needs do you feel have been met through your process as a primary caregiver?

Describe any changes in your style of living since becoming a primary caregiver.

Describe any changes in your occupation since becoming a primary caregiver.

What skills or assistance would help you most in your life as a primary caregiver?

Did you experience any differences after the diagnoses in 1) finances, 2) legal matters, 3) medical assistance, 4) housing situation, 5) emotional support, 6) spirituality/religion?

Procedure

The first phase of this study preceded the writing of the research proposal and took approximately nine months. This phase included exploring past research on Alzheimer's and the scope of caregiving. From this preliminary work, it was possible to speculate topics that primary caregivers may discuss during the interview process.

This research was an effort to learn more about the daily needs, struggles, and satisfactions that accompany the life of primary caregivers of Alzheimer's patients. Therefore, the research questions for the qualitative portion of the study assess the degree to which specific needs have or have not been met for the caregivers as they progressed through the stages of Alzheimer's with their loved one.

The first objective of the researcher was to understand more about the caregivers as individuals. Thus, this researcher attended several Alzheimer's support groups and adult day centers. In addition, the researcher attended the Governor's Conference on Alzheimer's Disease and several other programs related specifically to the disease. The following steps were followed in contacting Alzheimer's caregivers.

1. The caregivers were invited to participate in ethnographic interviews once the researcher became familiar with the format of the support group meetings and adult day centers. The caregivers from support groups were approached before or after the meetings and asked for willingness to be interviewed. In addition, support group coordinators were asked to encourage caregivers to share their story of caring for an Alzheimer's victim, when the researcher was not able to attend a specific support group. Participants were recruited and interviewed until response saturation was achieved (Joanning & Keoughan, 1998). Approximately 12 months were set aside for conducting interviews.

2. A comfortable meeting place for conducting interviews was established by each informant.

3. Each informant was given written information (Appendix A) about the study's benefits and risks and asked to sign an informed consent form, which explains issues of confidentiality and gives permission to audiotape the interview. Informants were notified that they could discontinue the interview process at any time.

4. Following the signing of consent forms, interviews began. Each respondent was first asked the grand tour question: "What has the process as a primary caregiver for an Alzheimer's patient been like for you?"

Although the researcher was interested in the overall process of caregiving for an Alzheimer's patient, more specific areas were also of particular interest. These more specific areas were sought through the use of the sub-questions mentioned earlier.

5. At the conclusion of each interview all audiotapes were transcribed and coded. In addition, a summary document was constructed and distributed to randomly selected respondents as a member check. Due to the length of the interviews summary documents

were not sent to every caregiver. These summaries were reviewed with the selected informants approximately one to two weeks after the initial interview to insure an accurate understanding by the researcher.

6. Data analysis was completed after all interviews and member checks were finalized (see Results section).

Indicators of Rigor

Credibility

Credibility in qualitative methods is similar to internal validity in quantitative methods. Establishment of credibility occurs when the researchers have accurately interpreted the informant's reality (Brotherson, 1990). Credibility is accomplished through a number of methods. The first technique is called a member check, which involves the researcher analyzing and summarizing the transcripts from each interview. These summaries are then offered to the respondent to confirm that the researcher's interpretations are correct. Second, a peer debriefing technique can be used to establish credibility. For this study, the researcher reviewed the progress of the interviews with her major professor. Progressive subjectivity was key in establishing credibility; that is, a journal was kept to document all research activity including personal reflections on the progress of the study. Finally, because this study utilized both qualitative and quantitative methods, triangulation of data was possible. Triangulation was emphasized through the use of multiple perspectives and methods, including interviews and survey instruments.

Dependability

Dependability (consistency) in qualitative research is similar to reliability in quantitative studies. In this study dependability was addressed through three primary

methods: audit trails, dependability audits, and triangulation. An audit trail describing all aspects of the research and the project's progress was updated continuously. A graduate student peer, conducted a dependability audit to assess the researcher's interpretations and research methods to ensure that consistency had been maintained. In addition, multiple sources, such as notes, audiotapes, and peer debriefing, were used in triangulating results.

Transferability

In quantitative research, the results concluded from the study are most useful if they are generalizable. In qualitative studies, a similar goal is known as transferability. That is, are the results from one context useful in other contexts? One method for establishing transferability was accomplished by sampling the range of informants who are current primary caregivers of an Alzheimer's patient. A second method included the development of a contextual description about caregiving by analyzing transcripts that offer an in-depth description of the participant's characteristics and life context.

Confirmability

Similar to the maintenance of neutrality in quantitative methods, confirmability ensured that all information provided through the interviews could be traced back to the original source and the theory used to develop interpretations (Guba & Lincoln, 1989). The two ways utilized to secure confirmability were through triangulation (the use of multiple methods) and member checks (asking the respondents to confirm whether the researcher's interpretations were correct).

Analysis

The interviews were conducted and analyzed through the use of transcripts from audiotapes of each informant's interview. Each audiotape and transcription was reviewed repeatedly by the researcher until the contents became familiar.

To begin, each transcript was read and notes were taken as each transcript was reviewed. As the transcripts were reviewed, each response to a question was reduced to one to two sentences. The point of minimizing the text was to grasp the main topic of the paragraph. The topics that were highlighted in more than one interview were grouped together.

All transcripts were reread with key words summarized in the margins (Joanning & Keoughan, 1998; Tesch, 1990). In addition, key words and topics were organized to form categories (Creswell, 1994). Creswell (1994) suggested that when developing a grounded theory, the researcher should attempt to saturate the categories through constant comparison of the respondent's stories. After close review of each transcript a code number or letter was assigned to the key words to organize all pertinent information from the transcripts by categories and eventually clusters. After the clusters were established, two to three of the most significant topics were selected. These most significant topics were labeled domains. Domains were made up of the major clusters that were highlighted throughout the majority of the respondents' stories.

Once the domains were established, data analysis moved to the next phase. The analysis was simplified through the use of computer software that allows all of the key words to be clustered together via a gathering function available on Windows 97. This software allowed the transcripts to be sorted by respondent, by key word, or by similar story lines.

The sorting task was accomplished by utilizing either the gathering function or the cut and paste option. This software program provided a more efficient way than manual cutting of transcripts of sorting and analyzing the information found in the transcripts (Creswell, 1994). A grounded theory was developed by combining the data analysis from the interviews and information gathered from the relevant past literature portion. After a grounded theory was established, the second portion of the study was ready to begin.

A secondary purpose of this study was to use a survey instrument to confirm the results from the qualitative interviews. The use of a survey allowed the researcher to determine if the results from the sample generalize to the greater Alzheimer's caregiver population.

Quantitative Methods

Informants

The informants for the quantitative portion of this study were 1) respondents in the qualitative portion, 2) part of a support group, 3) caregivers who took their loved one to an adult day center, or 4) caregivers who were sought out by word of mouth throughout the state. All but three of the participants from the qualitative portion were invited to fill out a questionnaire and provide comments about the questions asked. Three of the participants who were interviewed were not asked to partake in the questionnaire due to the loss of their loved one. The questionnaire was developed for current caregivers and included questions that would not have applied to past caregivers. Support group leaders, directors of adult day centers, and I provided the remaining caregivers with a questionnaire.

The Alzheimer's support groups and adult day centers that were selected for this study were based on the size of the groups and on the directors' interest in this disease. The

group leaders and directors who assisted in the distribution of the questionnaire have a great interest in Alzheimer's and understood the need for a questionnaire such as the one developed for this study.

Including the questionnaires distributed to the nine caregivers who participated in the interview process, the questionnaires were distributed to support groups, adult day centers, and community members. Fifteen questionnaires were delivered to individuals in a city with a population of more than 50,000 people. Eleven questionnaires were delivered to participants from a city with 20,000-50,000 inhabitants. Fifteen questionnaires were delivered to rural towns with populations of less than 15,000 people. Due to the overall population of the mid-western state in which this study took place, few minorities were included in this study. Second, because women tend to live longer than men and women tend to be regarded as caregivers, more women than men were participants in this study.

Measure

The questionnaire utilized in the quantitative portion of this study was formulated from a grounded theory based on the ethnographic interviews conducted in part one of this study. The answers given through the interviews were used to guide the collection of questions for the quantitative methods. After completing the interview process, the researcher found portions of existing questionnaires that seemed to correspond to certain aspects of the interviewee's explanations. However, there were some areas that could be explained better through the use of open-ended questions or additional questions that fit with the topic of an existing questionnaire but were not included by the original developer. The portions of existing questionnaires and the open-ended questions derived from the interviews were then arranged in a quantitative survey format.

Quantitative measures were used to assess whether a fit exists among the several caregivers' responses to a survey and the in-depth information provided by interviews from a few caregivers. Therefore, the questionnaire was used as a way to verify or disqualify the grounded theory developed by the researcher from the interview process.

The questionnaire was set up in a multiple choice and Likert-type format. Items were based on information gathered from the qualitative process; that is, the domain analysis was broken down into relevant items for the survey. In addition, this survey offered open-ended questions to find out more detailed information about the caregiver's experience. The respondents were asked questions related to his/her needs, struggles, and satisfactions as a caregiver. This extra section allowed this researcher to assess how well the questions represent the lives of the caregivers and pinpoint in greater detail the effect of Alzheimer's on the caregivers.

Several domains and clusters that were discussed in the interviews were compiled into the questionnaire given to the Alzheimer's caregivers. Caregivers were first invited to participate in the study and then asked to sign an informed consent form. Caregivers were told that the significance of the study was to understand better caregivers' needs, struggles, and strengths. After signing the consent form, caregivers were asked a number of questions, including demographics, a description of the Alzheimer's patient's current behaviors, how the caregiver currently feels, how the caregiver would describe the Alzheimer's doctor, a description of several key people in the lives of the caregiver and the patient, and a number of open-ended questions (see Appendix).

Demographics

The demographics section of the questionnaire included nine questions. The age, gender, and education level of both the caregiver and the Alzheimer's patient were of interest. Caregivers also were asked if they lived with the patient, their relationship to the patient, and the number of hours that they spend caring for the individual with Alzheimer's on a given day.

Alzheimer's Patient Behavior Checklist

This section of the questionnaire asked the caregiver to describe the individual they care for. The caregiver was asked to consider a number of situations that may have occurred through the past week before taking the survey. Caregivers were also asked the frequency with which a particular behavior has occurred.

The questions asked of the caregiver came from a reduced and slightly altered version of the Memory and Behavior Problems Checklist (MBPC) developed by Steven and Judy Zarit (1985) to measure problem behaviors in dementia patients. The original MBPC included 32 questions of behaviors and nine questions of activities of daily living to determine how frequently a particular behavior occurs in an Alzheimer's patient. The original MBPC had a split-half reliability of .65 for the problem checklist and a test-retest correlation of .80. The original MBPC had good concurrent validity with the Frequency of Problem Behavior Checklist and the Mental Status Questionnaire.

The items for this portion of the survey was scored similar to the original MBPC checklist. The answers to all questions were summed together to indicate overall severity of the present problems. The higher the overall scores, the greater the severity of the problems. For the purpose of the current study only 12 of the original 32 items were included. These

items included in the altered MBPC were selected because they seemed to fit best with the information given from the interviewees. Other questions from the original MBPC were excluded and were not relevant to the current study.

For the purpose of this study, caregivers were asked to rate the severity of a particular behavior beginning with zero if the behavior has never occurred through five if the behavior occurs daily or more often. The behavior was given a score of 6 if the problem occurred when the patient was not supervised. The behaviors listed in this portion include: trouble remembering recent events or significant events from the past and mixing up present and past. Caregivers were also asked to describe if the patient ever loses things, wanders, or doesn't recognize a certain place. Caregivers were able to share if the patient was able to start daily activities by himself or herself, was constantly agitated, was talking little or not at all, or had become suspicious or accusative. Finally, caregivers were asked if the Alzheimer's patient had become sad or depressed, or had a tendency to strike out or hit.

These are very difficult questions to ask a caregiver knowing that most of the Alzheimer's patients were their spouse or parent. However, the answers to the questions provided insight into the stage of the disease that the patient was in and the level of stress that the caregiver was dealing with.

Feelings of Caregiver Assessment

The caregivers were asked about emotional loneliness and feelings of social isolation. Caregivers were asked to respond with the number one if they felt a certain way most of the time, with the number two if they felt a certain way sometimes, and with the number three if they never felt a certain way.

The caregivers were to answer questions related to how much they looked forward to certain events, if they slept well, if they felt like crying, felt like running away, had lots of energy, felt lonely, or bored. These questions were developed for the quantitative portion of this study because of the interviewee's explanations about the emotional struggles of being a primary caregiver.

Attitude About Doctor Evaluation

The following portion of the survey was directed at a better understanding about the trust that caregivers have in the Alzheimer's patient's doctor. Questions were reduced and altered slightly from the Trust in Physicians Scale (TPS) developed by Lynda Anderson and Robert Dedrick (1990) that was created originally to measure patient's trust in their physicians. This portion of the questionnaire was added after many of the caregivers interviewed stated that they had mixed feelings about the Alzheimer's patient's doctor.

The TPS was first developed as an 11-item scale for the purpose of measuring patients' trust with their primary-care physicians. Trust was defined by Anderson and Dedrick as a person's belief that the physician's words and actions are credible, and can be relied upon, and that the physician is working in the patient's best interests. The original TPS had an excellent internal consistency, with alphas ranging from .85 to .90. In addition, the original version of the TPS had good construct validity correlating with sub-scales of the Health Locus of Control Scale.

Five questions were taken from the TPS, and two additional questions derived from the qualitative data were created for the purpose of finding out the caregiver's degree of trust in the patient's doctor. Five questions were selected from the original TPS based on their significance to the current study and from statements provided by the Alzheimer's caregivers

in part one. Trust was defined in the same way as intended by the original authors. The altered TPS was scored by reverse-scoring items 1, 2, 4, and 7 and summing all of the items for the total score. The original TPS required reverse-scoring on these same items and a similar analysis was used for the altered portion of the TPS. A higher score on both the original and altered version of the TPS reflects more trust for the physician.

Caregivers were asked to read the statements and respond with a level of agreement or disagreement. The scale from which to select the appropriate response ranged from one (strongly agree) to five (strongly disagree). Caregivers were asked if they doubt that the doctor cares about them and the Alzheimer's patient as a person. Caregivers were also asked if they believed that if the doctor tells them something, it must be true. Next, caregivers were asked if they believe that the doctor was doing everything that he or she could do for the Alzheimer's patient and if they believed that the doctor was an expert in Alzheimer's disease. The final portion of this section asked caregivers if they believed that the doctor gives adequate information about how to care for an Alzheimer's patient and whether the caregiver would consider a second opinion, if he or she distrusts the doctor's opinion.

Evaluation of Support System Checklist

The next component of this questionnaire was added as a way to receive information about the caregiver's opinion of individuals who may make up his or her support system. Caregivers were asked to place a check next to the classification that best describes the doctor that the Alzheimer's patient has seen throughout the disease process, and the caregiver's family support system, non-familial support system (friends, neighbors, and support groups), legal consultant, church community, and the Alzheimer's patient (current condition).

This portion of the questionnaire was modified from the Evaluation Of Others Questionnaire (EOOQ) developed by Jeremy Shapiro (1988) as a way to measure judgment about others. The original version of the EOOQ included a checklist of 38 items that assessed achievement, social skills, subjective well-being, and kindness/morality. The original EOOQ had no reliability data reported but had some concurrent validity when utilized with depressed patients.

The modified version of the EOOQ used in this study included 15 descriptive items. These fifteen items are suitable descriptors for numerous individuals and can express several characteristics of an individual. Caregivers were asked to place a check by the words that best describe the individual listed at the top of each column (i.e., doctor, family, non-family, lawyer, church, and Alzheimer's patient).

A wide range of descriptors was included as options for evaluation. These descriptors include kind, hypocritical, friendly, trustworthy, wise, phony, intelligent, ethical, competent, knowledgeable, dishonest, likable, helpful, loving, and easy to get along with. This section was added to the questionnaire to allow caregivers the chance to describe individuals who typically have a great impact in caregivers' lives.

In The Words of The Caregiver

The final page of the questionnaire allowed the caregiver to share some personal information about what it has been like to be a caregiver for an Alzheimer's patient. First, caregivers were asked if they had a job outside of the home in addition to caring for the Alzheimer's patient, and, if so, how many hours they worked outside of the home. Caregivers were also asked if they participated in support groups and if they took advantage of respite options.

Caregivers were also invited to answer a number of open-ended questions. The caregiver was asked to list any areas in which he or she wished more help were available. Next, the caregiver was asked to state any modifications that needed to be made to the home where the Alzheimer's patient currently resides, because of safety reasons or ease of care. Third, the caregiver was asked to list any suggestions that he or she had that would have made caring for an Alzheimer's patient easier. The caregiver was then asked to best guess what stage they believe the Alzheimer's patient that he or she cares for is currently in (early, middle, or late). Caregivers were then given the opportunity to provide strengths, happy times, or satisfactions in caring for an Alzheimer's patient. Finally, caregivers were asked to state any additional comments that they would like to add to help the researcher understand better the needs, struggles, and satisfactions in caring for an Alzheimer's patient.

Procedure

The relevance of the quantitative methods portion of this study was to generalize from the sample of Alzheimer's caregivers in part one to the population of all similar Alzheimer's caregivers. From this sample and the caregiver's story, inferences were made about the characteristics, behaviors, needs, and attitudes of this population (Babbie, 1990).

The qualitative interview process in part one took from one to three hours with every respondent. Consequently, a questionnaire that took 10-20 minutes to complete was developed to allow several caregivers the opportunity to provide information regarding their experience in an efficient manner.

The caregivers who participated in the quantitative portion, much like those who participated in the qualitative interviews, were individuals who are involved in Alzheimer's support groups, or adult day centers and those contacted by word of mouth. Individuals

involved in the interview process were asked to participate in the quantitative portion of the study and provide suggestions for any changes or additions that should be made to the questionnaire. That is, the group included in the qualitative portion was asked if the quantitative portion of the study was representative of the information provided through the in-depth interview process.

From this researcher's experience, the following procedure was convenient and efficient. The researcher has found success by handing out surveys and questionnaires through face-to-face interaction. For this study, the researcher was able to meet most of the participants through the support groups, adult day centers, and the interview process and provide them with a questionnaire that could be mailed back to the researcher upon completion. The researcher believes that caregivers may feel more comfortable responding to the survey if they have been acquainted with the researcher.

Questionnaires were distributed over three months and were collected via mail. Nine questionnaires were delivered to the caregivers who participated in the interview process. After the collection and assessment of these nine questionnaires, twenty-one questionnaires were offered to members of an Alzheimer's support group, with 16 going to adult day centers, and four questionnaires went to people the researcher had met throughout different communities.

The surveys that were given to the individuals who participated in the interview were entered and analyzed as a pilot test to assess whether the questions were understandable and comprehensive in the areas that emphasized the main needs, struggles, and satisfactions of the caregivers. Data analysis on the pilot test questionnaires included basic frequencies and review of responses. Following the pilot test analysis, two minor changes were made to the

questionnaire: 1) the "current" and "condition" were added to the descriptor of the Alzheimer's patient on page six of the questionnaire and 2) a statement was added to the last page of the questionnaire ("feel free to add comments on the back of this form"). Because the changes were added for clarification and did not significantly change informants' outcomes, the data from the pilot test were added to the results from additional informants.

The questionnaire took approximately 10-20 minutes for each individual to complete. The questionnaire and a self-addressed return envelope were given to each caregiver. The survey was delivered to each caregiver by an adult day center director, a support group leader, or myself. Caregivers or support group leaders were given a follow-up letter or phone call two weeks after the distribution of questionnaires.

Analysis

Frequencies and distributions were conducted on all variables from the nine caregivers who participated in both the qualitative and quantitative portions of this study. These caregivers who completed the questionnaire did not state that any errors existed in the survey or that any changes needed to be made. However, several of the caregivers felt that it was necessary to provide additional information about the patient or the caregiver. Therefore, future caregivers were encouraged to provide additional comments on the back of the questionnaire.

Once the data from the pilot study had been fully assessed, questionnaires were offered to additional caregivers who did not participate in the interview process. Survey completion from additional caregivers would provide a wealth of information to further the development of this questionnaire.

A reliability test was completed on all four of the main components of the questionnaire. A test for reliability using Cronbach's alpha was conducted on the Alzheimer's Patient's Behavior Checklist resulted in a reliability of .72. The Feelings of Caregiver Assessment scale had a Cronbach's alpha score of .81. Furthermore, a reliability of .79 was concluded from the Attitude About Doctor Evaluation. Finally, a Cronbach's alpha score of .95 was produced as the reliability for the Evaluation of Social Support Checklist.

The completion of the questionnaire by the interviewees, along with basing the questionnaire on interview data, enhanced both face and content validity of the instrument. Face validity was established by asking caregivers if the instrument adequately assessed caregivers needs, struggles, and satisfactions. Content validity was established by constructing the clusters and domains from the interviews to develop each section of the questionnaire. By formulating the questionnaire in this way, each portion of the instrument represents what the questionnaire was designed to measure.

Following the checks for validity and the tests of reliability, frequencies, cross-tabulations, and factor analysis were conducted on all variables in the questionnaire. Results and discussion from the interview process and from the questionnaire are found in chapter 4.

CHAPTER IV

RESULTS AND DISCUSSION

Qualitative Results

The twelve primary caregivers involved in the interview process of this study provided wisdom that only a caregiver could describe fully and adequately. Subsequent interviewees shared information that allowed for congruencies and uniqueness from each other caregiver's experience. Following the collection of interviews, stages of caregiving evolved dependent upon the state of the Alzheimer's patient. In addition, trends developed in the need for particular assistance or from specific practitioners in caring for the Alzheimer's patient. Caregivers also expressed the meaning-making that described their caregiving experience. Demographics of interviewees were assessed prior to meeting the respondents.

Demographics

Prior to interviewing respondents the following information was noted: gender of caregiver, population of caregiver's town or city, and race. There were ten women and two men included in the interview process. Five of the caregivers lived in a city with a population of more than 50,000 six lived in a city of 20,000-50,000 people, and one person lived in a town of less than 15,000 people. All of the caregivers were Caucasians. The race of the caregivers is representative of the elderly population of the mid-western state and of the disease.

The caregiver's relationship to the Alzheimer's patient, type of housing in which the caregiver resided (house, assisted living, apartment), and whether the Alzheimer's patient lived with the caregiver were also noted before the interview process. Five of the caregivers were caring for their spouse, five were caring for their mother, one was caring for an aunt,

and one was caring for a close friend who happened also to be a neighbor. Nine of the caregivers lived in a house, one lived in a townhouse in an aging community, and two lived in an apartment within an aging community. Seven of the interviewees provided care in their own home and five provided care in the patient's home.

Through the interviews it became apparent that three of the caregivers had lost their loved one recently due to complications associated with Alzheimer's. Furthermore, three caregivers either had decided or were in the process of deciding to send their loved one to a nursing home, and six of the caregivers currently were caring in their home or in the house of the Alzheimer's patient.

Introduction to Respondents

A brief description of each caregiver has been provided to introduce the respondents who participated in the interview portion of this study. Each caregiver is described in greater detail throughout the rest of chapter 4. Names of the caregivers were not included to maintain confidentiality.

Caregiver #1 is in her late eighties and cared for her husband who had passed on recently. She cared for her husband, the patient, in their home until he passed on.

Caregiver #2 is in her mid seventies and is widowed. She cared for her mother who had passed on recently. She cared for her mother in her own home until the patient passed on.

Caregiver #3 is a 58-year-old female. She is currently married and self-employed. She cared for her mother in her mother's home.

Caregiver #4 is in her late forties. She is currently married with two children. She cared for her mother in her own home.

Caregiver #5 is in her early seventies. She is currently married and cares for her husband, who recently was moved to a nursing home.

Caregiver #6 is in her late seventies. She is currently married and cares for her husband in her own home.

Caregiver #7 is in her late fifties. She is not married and cares for her friend/neighbor in the patient's home.

Caregiver #8 is in her late fifties. She is not married and cares for her aunt in her aunt's home.

Caregiver #9 is a man in his early eighties. He cared for his wife in their home until she passed on.

Caregiver #10 is in her late forties. She is currently married and cares for her husband in their own home.

Caregiver #11 is in her early fifties. She currently cares for her mother in her mother's home.

Caregiver #12 is in his early fifties. He currently cares for his mother in his mother's home.

Grand Tour Responses

The interview process for each caregiver began the same way. Each caregiver was asked the grand tour question: What has it been like for you to be a primary caregiver of an Alzheimer's patient? Each caregiver had an interesting response to this question. Each response was unique, yet similarities existed among caregivers who were caring for an Alzheimer's patient within the same stage. Those who care for patients in the early stage of the disease began the interview with statements such as:

Caregiver #13 *"As much as possible I try to maintain my sense of humor rather than holding pity parties for myself."*

Caregiver #6 *"I am not sure how helpful I will be, because I have only been at this for one year."*

The similarities in those who cared for a patient in the early stage of the disease included minimization of the time commitment to caregiving and a very optimistic view of caregiving. Three of the four caregivers were caring for patients who had manifested symptoms for one year or less. The remaining caregiver had cared for his mother who had shown symptoms for past three years. The classification of caregivers seemed to be related to their interpretation of caregiving and the severity of the Alzheimer's patients' behaviors and less to the number of years they had been a caregiver. However, those who had been caregiving for several years were more likely to be in the middle or late stage of caregiving (See Middle and Late Stage of Alzheimer's).

Unlike those who cared for someone in the early stage of the disease, those who were caring for someone in the middle stages began with statements that described the difficulty of caring for someone with Alzheimer's and how overwhelming the job was. Although the two caregivers in this segment had been caring for an Alzheimer's patient for two and three years, respectively, both stated that symptoms had started before the patient's diagnosis. One caregiver had this to say in response to what it has been like to be a primary caregiver:

Caregiver #10 *"I will do whatever I can to help people to better understand this disease. It is just a really hard job. It's just, being a full-time caregiver of an Alzheimer's patient or person is so devastating. It robs you of everything. It is something that nobody should have to do."*

Those who care for someone in the late stages literally described how their life as a caregiver began. One of the caregivers had been taking care of her husband for ten years. The other two caregivers had been caring for their mothers for thirteen and fifteen years, respectively.

Caregiver #3 *"Others thought that she was just wanting attention, which she did like to be the center of attention (laugh). But, it was frustrating because you knew, I knew that she wasn't really understanding what was going on. But, I know others, even in the family, wouldn't accept it.*

Caregiver #4 *"We lived here with my mother for two years, we moved in with her because we realized something was wrong. And she needed me to be here. We had an idea it was Alzheimer's, we didn't know for sure until we moved in with her."*

For those caregivers whose loved one was deceased, it seemed important for the caregiver to describe the patient in detail, including information about the individual before the onset of the disease. The first caregiver who was interviewed had lost her husband. The researcher was greeted with pictures of him and the family that they shared, upon entering her apartment. The second caregiver shared the autopsy report of her mother. All three of these caregivers spent time describing attributes that the patient had prior to the disease. Caregiver number nine described his wife as wonderful. Caregiver number one described her husband as once having a photographic memory. Caregiver number two described her mother as unique, and noted that because of her persona Alzheimer's initially was difficult to detect.

Through these initial responses to the grand tour question, it became apparent that caregivers shared similar characteristics with other caregivers who cared for an Alzheimer's

patient within the same stage. That is, caregivers who assist an Alzheimer's patient in the early stage of the disease tended to share similar stories about their experience in caregiving. This trend continued for those in the middle stage, the late stage, and those who had lost a loved one due to complications of Alzheimer's.

Stages of Caregiving

Each caregiver, with the exception of those who had lost their loved one, was asked to assess what stage he or she believed the Alzheimer's patient currently was in. Three caregivers had lost the loved one for whom they had cared. Furthermore, four caregivers believed that their loved one was in the early stages of Alzheimer's, two caregivers believed that their loved one was in the middle stage, and three caregivers believed that the patient was in the last stage of the disease process. The stages listed previously were used as a guide for the caregivers to assess the patient's current status.

Early-Onset Alzheimer's

It should be mentioned that one respondent was caring for her spouse who had been diagnosed with early-onset Alzheimer's. This respondent's husband was diagnosed at the age of 50. She was in her late forties and had been caring for her husband for the past three years. This caregiver lived in the same home that she and her husband had shared for more than two decades. This caregiver was very educated about early-onset Alzheimer's and knew that this type moved quickly through the disease process. Therefore, in case she was no longer able to keep her husband at home, she had him on a waiting list at a respected care facility.

This caregiver believed that her husband's diagnosis was of the familial type. She stated that every generation had been affected by the disease 20 years earlier than the next

generation. Her husband's grandparents were in their eighties, his mom was in her sixties, and he was 47 when she first started seeing signs. She stated her concern for her children and the possibility of them inheriting Alzheimer's of the familial type. All of her children were tested, but because of the possible loss of insurance the test results have not been delivered to her or her children. Her children have stated to her that they would not want to know the results even if they could. This caregiver seemed to know of at least five other families within the state who also had a family member suffering from early-onset Alzheimer's.

Her story was especially unique because of the rareness of early-onset Alzheimer's. Only one caregiver had cared for someone with early-onset Alzheimer's disease. Therefore, this caregiver serves as the best representative of an early-onset caregiver. This caregiver discussed the stages that may be encountered when caring for someone with early-onset Alzheimer's. This caregiver described her husband as currently in the middle stage of the disease process. This caregiver described her process to present as such:

Caregiver #10 *"I constantly feel like my heart has broken into pieces and smashed. Every time I feel like, oh this was a good day, something will put you right back down in the pits. You can't compare this to anything else. With us we grieve forever, it goes on forever. I don't know if it is so mentally exhausting that physically it breaks us down or so physically exhausting that mentally it breaks us down."*

"You go through all stages. In the beginning it's anger and I have been through terrible depression. In the beginning the depression was just horrible. You go through them constantly. You don't go through the anger and then the anger is gone and then another stage begins. Tomorrow it will be anger, then the next it will be depression, the next day everything is just funny. The emotions go on constantly."

Early Stage of Alzheimer's

Aside from the caregiver of the early-onset individual, the remaining caregivers seemed to have similar characteristics dependent upon the stage of the patient. In the early stage of Alzheimer's the patient typically is dealing with mild confusion, mild communication difficulties, impaired judgment, and loss of recent memory. Four caregivers expressed that the individuals they cared for were in the early stages of the disease process and asserted that caregiving at this point was not too difficult. While some adjustments had been made to the Alzheimer's patient's home and three of the four caregivers were no longer employed, caregiving responsibilities did not seem overwhelming to the caregiver. In fact, all four of these caregivers mentioned more than once that they were not sure how helpful they would be in the interview because they were so new at caregiving.

One of the caregivers was in her late seventies. This caregiver was caring for her husband who was in his eighties. She mentioned that she cared for her husband 21 to 24 hours a day. The other three caregivers were in their early fifties and the Alzheimer's patients were in their late seventies, early eighties, and early ninties. All three of these caregivers stated that they cared for the Alzheimer's patient up to five hours per day and currently did not live with the Alzheimer's patient.

One caregiver had already retired and was able to care for her husband who also had been retired for almost 15 years. The other three caregivers no longer worked on a full-time basis. One of these caregivers assisted her aunt on a daily basis, one assisted a close friend, and one cared for his mother. All three of the caregivers mentioned that the Alzheimer's patient they cared for did not require supervision 100 percent of the time. However, the respondent who cared for her husband did mention that she was not able to leave him alone

because of multiple health problems. In the interview the caregivers stated what it was like to care for an Alzheimer's patient:

Caregiver #7 *"I go to her house and we enjoy watching television together."*

Caregiver #8 *"I find it pleasant to be a caregiver. I enjoy it"*

The caregivers in the early stage tended to share more positive than negative aspects of caregiving. The caregivers stated:

Caregiver #7 *"I don't feel overloaded because I am only with her six hours. I hear so many others share their experience and I realize that I am not that bad off."*

Caregiver #6 *"I have been married for 55 years, I feel this is part of my duty. I don't resent it."*

However, negative aspects of the disease were more likely from the caregiver who was a spouse than from the other caregivers. Not surprisingly, this caregiver was living with the Alzheimer's patient, unlike the other three caregivers. This caregiver stated some of the negative aspects of caring for her husband who is battling with this disease:

Caregiver #6 *"The hardest part of caregiving is cleaning up after he soils himself. It is really the emotions of it. It is hard having to clean up your husband. It is also hard because he hasn't talked much in the past year and so he doesn't ask me how my day is."*

The caregiver who was caring for his mother mentioned some negative comments that seemed to relate to the failing health of both of his parents and not specifically about caregiving for the Alzheimer's patient. This caregiver left his job in another state to move near his parents and provide care for them.

Caregiver #12 *Summer of 1996: My mother continually repeated herself as she's done for the past couple of years. The day after Labor Day: My father went in for routine*

gallbladder surgery. October, 1996: My aunt called me and told me to get home ASAP. My dad was taken to the hospital for emergency surgery. Infection from the gallbladder had invaded his spinal cord. My aunt and mother picked me up at the airport. When we got to the hospital my aunt cautioned, "Watch her."

Middle Stage of Alzheimer's

In the middle stage of Alzheimer's the patient typically becomes very disoriented, and has moderate to severe complications in communication, poor judgment, and difficulties with daily activities (i.e., bathing, dressing, and eating). Two of the respondents described the Alzheimer's patient that they care for as being in the middle stage of the disease process. One of the caregivers with a loved one in the middle stage was mentioned earlier in the description of early-onset Alzheimer's. This caregiver is in her late forties and is caring for her husband. The other caregiver is a woman in her early fifties and caring for her mother, who is in her late seventies.

The career of these caregivers was very interesting. The woman who cared for her husband stated that she decided to go back to work to get a break from caregiving. She stated that it is extremely expensive to have someone stay with her husband but she realized the need for a break from caregiving. She had this to say about going back to work:

Caregiver #10 *"I work two and a half days a week. I just now went back to work simply because of my own mental health. I knew I was going to get a job in the fall. I am working part-time. I couldn't work at a job with stress. But, I have to have somebody with him while I work."*

The caregiver who cared for her mother was a nurse and decided to quit her job two years ago when her mother was diagnosed. This caregiver stated that she was an only child

and lived 220 miles away from her mother. This caregiver had this to say about her experience as a nurse and how that applied to her mother's health:

Caregiver #11 *Sometimes even though I am an R.N. with many years of nursing home experience, I feel absolutely overwhelmed.*

Unlike the caregivers who cared for an individual in the early stage of the disease, these caregivers understand the wealth of complications that arise because of this disease. One caregiver stated that she had faced several complications because her husband was the financial supporter for the family and he owned his own business. She was now responsible for his business deals and for meeting his needs in the home. She felt that he could be left alone for only an hour or two at a time and he usually was tended to in their home 24 hours a day.

The other caregiver assisted her mother up to five hours a day. The Alzheimer's patient has become accusative toward her daughter for not allowing her to drive. The patient also has trouble remembering recent and past events. The caregiver described the patient as being obsessed with certain activities that were done in the home (i.e., going downstairs and putting in water softener).

Both of these patients still have the ability to communicate with their caregivers but find it difficult to complete sentences without assistance. These caregivers stated that this stage of caregiving was a shock to their system. The time, emotional and financial dedication to caregiving at this stage was described as overwhelming.

Caregiver #11 *"It is very different having a parent with this disease than going to work for 10 hours and then forgetting about it. I worry everyday about my mom."*

Caregiver #10 *"A full-time caregiver doesn't have a life. Everything is too overwhelming in the beginning. First you are just trying to deal with the diagnosis. I could only handle, cope, deal with x amount of things at a time."*

Changes in both the characteristics of the patient and in caregiving seem drastic when comparing the early stage of the disease process to the middle stage. Caregivers who were assisting in the middle stage expressed a much greater level of loneliness and isolation. These caregivers described their emotions with more negative descriptors than did those in the early stage of the disease.

Caregiver #10 *"When you are a caregiver, you are totally isolated. In its own way it is a disease and sickness to be in one building with one person 24 hours seven days a week, week after week. It is not healthy. It has got the best of me."*

Late Stage of Alzheimer's

Patients at this stage experience the loss of control of bodily functions, loss of communication, and the inability to perform daily activities. Three of the respondents described the individual that they care for as being in the late stage of the disease. Two of these caregivers were caring for their mother and the third was caring for her husband. All three of these caregivers had either made the decision or were in the decision process of placing their loved one into a nursing home. These caregivers were unlike the caregivers described in the early stage or middle stage process. One caregiver had this to say about her caregiving experience:

Caregiver #5 *"Living with and caring for an Alzheimer's patient is a living hell. And some things are so comical. Lots of laughs and lots of tears. Stressful. Lonely. The person is there, but is not there."*

These caregivers were able to give specifics about things that the Alzheimer's patient had said or done. These caregivers expressed how difficult caregiving was and the changes that had to be made to accommodate caring for an Alzheimer's patient. One of the caregivers had already retired, the other two caregivers had to adjust their work schedules in order to better care for their mothers.

Caregiver #3 *"My work is flexible, I was in and out quite often checking on her. I was in and out several times, different times in the morning or afternoon, to make sure she was okay."*

Caregiver #4 *"I was a secretary for awhile, and somebody was always home. Somebody had to be here for her. We paid our kids, we had to pay our own kids to stay here."*

These caregivers stated that some aspects of caregiving were more challenging than others. Notably, reckless driving, incontinence, and wandering were mentioned as the most challenging aspects of the disease process, itself. Other challenges were stated and will be discussed in the following section entitled needs, struggles, and satisfactions in caregiving. Caregivers of patients in the late stages shared the following about experiences with changes in driving and wandering.

Caregiver #4 *"We really needed a lawyer to sell the car, because I didn't want her to drive anymore. When she turned a corner she'd go to the center lane. Then she had car accidents."*

Caregiver #4 *"My husband just happened to get up to use the bathroom around five am and saw the front door open. And then she was not in her bedroom, so we called the police. Then about a half and hour later the police station called and they found her and*

they brought her home. Her hands were very bloody. I cleaned her up and took her to the hospital and they had to put 18 stitches in her finger."

Recently Deceased

These caregivers were unique in how they described their deceased loved one's. Two of these caregivers had lost a spouse and one had lost a mother to Alzheimer's. Two of the three caregivers shared the documents of the autopsy report. Both reports described a presence of Alzheimer's in the individual.

These caregiver's descriptions of the patients were extremely detailed. In all three of these interviews, respondents' description of the Alzheimer's patient and their family included photos of family members or an in-depth history of the individual's life. While details about the patient's disease process were vivid, respondents also described the patient's life before the onset of Alzheimer's, and how the disease affected them as a caregiver.

Caregiver number two shared an interesting history of her mother's survival of a concentration camp. Her mother was a survivor who barely escaped with her life to America. In fact, her mother's sister did not survive the concentration camp. In her mother's late stages of Alzheimer's, she had regressed back to her childhood and spoke only in German. Luckily she was able to understand her mother in order to meet her needs.

Caregiver number one described her loved one with great respect.

Caregiver #1 *"When he was in college, he said that he could mentally read his notes, when taking an exam for example. He remembered them so well, and he was tops in his class. He graduated with a major in agricultural economics, and agriculture. He was a*

farmer. He went back to the farm. And we lived on the farm the first couple of years and then, the depression and drought of the thirties hit and we came to Iowa."

Two of these caregivers had retired prior to the onset of the disease and one caregiver had to adjust her career to care for her mother. The two caregivers who were retired regarded their experience as a duty to care for their spouse. In fact, these caregivers had this to say about caring for their spouse:

Caregiver #1 *"It didn't seem like a burden. I think I was lucky to have him as long as I did. I don't think that I ever felt that it was not fair or that things should have been better."*

Caregiver#9 *"I didn't want to admit it and I was in denial for a long time. It didn't seem possible that such a wonderful lady could have such a horrible thing happen to her."*

Similarities Among Caregivers of All Stages

There was an interesting realization by this researcher after assessing the information from all twelve caregivers. Nine of the twelve caregivers mentioned that something was definitely wrong with their loved one. In fact, five of the caregivers stated that they had noticed a significant change in the patient's cooking or orientation in a kitchen. All five of these patients were female.

Caregiver #9 *"One of the first signs was that the kids noticed a big change in her cooking. She had always been an excellent cook and loved her kitchen more than any area of the house. Once she started to forget things, her cooking went downhill."*

In addition to changes in cooking, four of the caregivers stated that they first noticed in the patient's driving. Two of these patients were male and two were female.

Caregiver #4 *"She had car accidents, she ran into the back end of somebody. It wasn't very much damage, she was going the wrong way on a one-way street. When the police officer got there she didn't know her first name, couldn't say her last name."*

Caregiver #10 *"He had a car accident, but that was way back in the beginning. He was diagnosed in August of '96. In December of '96 he was driving down the street and I know what he did just as sure as I am sitting here because that was one of the signs that I knew something was wrong because his driving skills were horrible. He went to make a right hand turn and he turned right in front of a pick-up. I know he didn't see this pick-up. That when I said, that's it. I am taking your license away from you. That was a major battle, lots of tears."* Interestingly enough, this caregiver mentioned that when her husband's mom was diagnosed, her husband said "mom can't cook right anymore, mom doesn't cook like she used to."

Caregiver number four had little problem with getting her mother to stop driving because of the accident. The other three caregivers had difficulties in trying to get their loved one to stop driving.

Caregiver #11 *"We had such a difficult time with her giving up driving. We finally disconnected the coil of her car, left a note on her steering wheel saying, We love you mom but please don't try to drive. Another note under the hood with my phone number, if she called a mechanic."*

These difficulties expressed by caregivers started several discussions about other difficulties that they encountered. Caregivers began to express numerous areas where assistance from others was necessary. Caregivers also stated a number of struggles that developed throughout the disease process.

Caregivers' Needs, Struggles, and Satisfactions

Each caregiver provided information about his or her needs, struggles, and satisfactions throughout the disease process. That is, some of the needs and struggles were dependent upon the stage that the Alzheimer's patient was in. Some caregivers' needs seemed more dependent upon unfulfilled expectations from specific individuals.

Caregivers' Needs and Struggles

Caregivers' needs are defined in this study as a necessity that a caregiver had requested assistance from another individual, including family, friends, the church community, lawyers, doctors, and support groups or adult day centers. Caregivers' needs were described as either fulfilled or not fulfilled. Caregivers' struggles, on the other hand, were defined as situations that the caregiver had difficulty dealing with. Caregiver struggles included how to deal with incontinence, wandering, reckless driving, or other problem behaviors. Caregivers' needs and struggles were described within the categories financial assistance, legal assistance, medical assistance, housing modification assistance, emotional assistance, spirituality, and caregiver stress.

Financial Assistance As mentioned previously, caregivers are more likely to be females than males. Of the females interviewed, six out of the ten no longer worked, three worked part-time, and one worked full-time. Each caregiver has had to deal with financial problems or situations to some extent. The caregivers who assisted their parent, a friend, or aunt seemed less financially responsible for the Alzheimer's patient than did those who cared for a spouse.

Caregiver #10 *"There is entirely too much to cope and deal with. The trauma of the decision, the diagnosis, your whole life changes, your dreams are all gone, everything that*

you hoped for is all gone. You have to learn to live differently. He was the sole income for us. I just worked part-time for fun. He was the breadwinner so we had to financially totally readjust our lives. It takes a lot of time."

Of the five caregivers who cared for their spouse, two mentioned how lucky they were to have known how to deal with the financial aspect of their lives. The other three caregivers, who were all females, had to learn how to deal with some financial aspect. Caregiver number six mentioned that she took over the finances when her husband was no longer able to sign his name on checks.

In addition to learning how to manage the patient's checkbook or business deals financially, some caregivers expressed the financial cost of caregiving versus working. Four of the twelve caregivers were already retired at the time of diagnosis. The remaining eight caregivers had to adjust their work schedule to become a caregiver.

Caregiver #10 *"I pay eight dollars an hour for this lady to stay with him from the time she leaves home until the time she gets back home. I get paid six dollars an hour. It costs me two dollars an hour to work, but it is for my sanity."*

Legal Assistance The legal assistance mentioned by caregivers was in regards to what action needs to be taken care of by the Alzheimer's patient and what needs to be done by the caregiver. Caregivers were also uncertain if there was a particular sequence of steps that needed to be followed when completing certain documents.

Caregiver #10 *"There is a lot of controversy whether you need guardianship and power of attorney. The legal system is so confusing and what you actually do need. I wish I would have been told about what paper work needed to be done right away."*

Caregiver #5 *"I hear a lot of conflicting advice and options to my legal questions."*

Two caregivers stated that their lawyers were helpful when assisting with things such as selling cars or estates. Seven of the caregivers had not felt that they needed a lawyer or legal advice thus far.

Caregiver #1 *"We had made our wills before this. There were no problems selling our estate, but I was certainly glad that I was as familiar as I was with our financial situation.*

However, most of the caregivers mentioned that their lawyers were not knowledgeable about Alzheimer's or dementia. One caregiver had this to say about her lawyer's knowledge of laws and rules.

Caregiver #10 *"Lawyers have been helpful, but they don't know enough about the system. The government changes their rules and regulations so often. I have sought legal advice from day one and it seems like everyone I see tells me something different. One will say do this and the other will say, do that. I finally decided to go with my gut feeling. I found I can't depend on other people."*

An interesting point was discussed with the caregiver of the early-onset patient about legal matters. She mentioned that because of her age she was not eligible for many forms of legal or financial assistance that is provided for those over the age of 65. Furthermore, she felt that she was not given the same financial and legal assistance because of her husband's young age.

Medical Assistance According to caregivers, this component included medical assistance that they needed for themselves and assistance that the Alzheimer's patient needed. Caregivers often began with description of the Alzheimer's patients' physician. Some of the caregivers described the doctor as helpful, some stated that the doctor was not

helpful. Two caregivers sought out specialists at the Mayo Clinic. These caregivers spoke very highly of the assistance that they received from the doctors at Mayo.

Caregiver #10 *"My general practitioner said that he didn't know anything about Alzheimer's, but that he would do all that he could do to help me find out about it. I am young enough and I am going to challenge the doctor. I challenge him and I ask questions."*

Caregiver #3 *"It was a little disappointing that area (medical) I think, my aunt and another aunt had taken her to the hospital because we thought she might be able to get my mother to admit something was wrong. But the doctors just kind of shrugged it off as old age."*

Caregiver #1 *"They didn't know. I can't say that I got much information from the doctors. I learned most of my information from my own observations."*

Caregiver #3 *"With the doctors, you don't get the physical time, or really the chance to talk to the doctors as much anymore. They are all business and that's it. I'm really disappointed in a way. I think they could have taken a little more time and checked and done a little bit more for her."*

Caregivers were comfortable discussing exactly what they did need from their doctor. Some caregivers described how they wished their doctors would speak with them. Others stated what kind of information the doctor could have given them to help them.

Caregiver #10 *"I wanted all the doctors to be straight-forward. It is the only way that I can comprehend it. To him-haw around about it (Alzheimer's) you never face it. The very best thing is that you know up front."*

Caregiver #11 *"I needed a simple book on Alzheimer's for the person who has just been diagnosed."*

Not only did the caregivers desire information about Alzheimer's, they needed assistance in better understanding some of the dangers and illnesses that often accompany Alzheimer's. These dangers and illnesses included depression, malnutrition, numerous hours of sleeping, wandering, falls, incontinence, and pneumonia.

Eight of the twelve caregivers stated that the Alzheimer's patient had gone through feelings of depression in the early stage of the disease and through the time of diagnosis. Two of the caregivers went as far as saying that they were concerned about the patient being suicidal in the early stage of the disease.

Caregiver #6 *"Earlier this year he was terribly depressed. He wasn't quite sure why he was here on earth."*

Five of the twelve caregivers stated that eating or malnutrition was a concern in the past or currently. Three caregivers stated that the patient would hide food that could have rotted if not discovered by the caregiver. Two caregivers were deeply concerned about the patient's eating habits.

Caregiver #3 *"I'm sure she wasn't eating properly. She didn't eat what she really should be.*

Caregiver #9 *"I would always make her chocolate milkshakes and that's all she would have for a very long time. Once in a while she would eat a bowl of cereal for breakfast but then she wouldn't feel like the milkshakes."*

Six of the twelve caregivers stated that they had a concern about the patient's sleeping patterns. Four of the caregivers described how the patient would get up in the middle of the night ready to start his or her day. These caregivers suggested some interventions that they had used to soothe the person back to sleep. Others stated that hospital beds or beds with bed

rails were necessary. Two caregivers stated that the patient slept an excessive number of hours per day.

Caregiver #6 *"He has a hospital bed. He sleeps during the day. When he sleeps, I take a nap."*

Caregiver #9 *"She was used to getting 8-10 hours of sleep a night but as the later stages came, she started to sleep 15-16 hours a day. Even when she was awake she never seemed to have much energy."*

Wandering seemed to be a danger for many of the Alzheimer's patients. Five of the caregivers stated that the Alzheimer's patient that they cared for had wandered away from the home at least once. Four of the five caregivers stated that at least one bad outcome had resulted from the patient's wandering.

Caregiver #4 *"This facility took short-term patients. We had her there for about four days, we were going to Chicago to see my brother. She was crying and crying, I couldn't stop her. I just left and told the staff, you'll have to calm her down, I can't do it. She got out on a Sunday afternoon. She started walking north in the middle of the highway. Pretty soon a couple found her and decided that maybe this lady came from that nursing home."*

Caregiver #9 *"Towards the later stages, she would just get up and walk out of the room down to another person's room on our floor. She would just open the door and walk in! That was the most embarrassing for me."*

Five of the caregivers mentioned that the patient had fallen at least once. One caregiver believed that her husband was falling due to a side effect from his medication.

Other caregivers described that the patient had fallen while wandering. Two caregivers described how the patient had to seek medical assistance because of the fall.

Caregiver #1 *"He was in the hospital once or twice. He fell and broke his arm. That didn't put him in the hospital, but it did take him to the doctor, of course. Thank goodness it was an uncomplicated kind of break and the doctor taped his arm. When we got home, I was busy with the mail in one room and he was in the kitchen, took a knife, and said this doesn't belong on my arm. He took it all off. We had to go back to the hospital."*

The condition that seemed to be most bothersome to caregivers was incontinence and encopresis. Six of the twelve caregivers discussed incontinence during their interview. One of the caregivers stated that her husband was not incontinent, but that his becoming incontinent would be so bothersome that she would then consider placing him in a nursing home. The other five caregivers stated that the person that they cared for was incontinent. These caregivers stated that incontinence was one of the worst aspects, if not the worst aspect, of caregiving.

Caregiver #1 *"He became incontinent and that was a nuisance, that's all it was. When he became incontinent, I didn't understand what it was. I didn't understand how to handle it."*

Caregiver #12 *"When you have Alzheimer's and can't remember that it isn't just gas you're passing, the results are messy."*

Caregiver #9 *"The last six months were very bad as far as incontinence and bladder control. Many nights she would wet the bed and she would sometimes wet her pants as well during the day. This got to be embarrassing as well. That was the most unpleasant day I can*

remember, when I had gotten up and she had left a trail of poop from her to where she was going. I'll always remember that."

A final topic that concerned caregivers was pneumonia. All three of the caregivers who had lost their loved one described some form of pneumonia or physical illnesses as a cause of their death.

Caregiver #1 *"His plumbing filled up and choked his heart. And he couldn't breathe. They had to put him on oxygen the last few hours, and they asked if he should be taken to the hospital, and I said no."*

Three of the caregivers stated that beyond the health of the patient, they, too, had developed health problems due to caregiving. One caregiver mentioned the physical strain she experienced from giving her husband baths. Two other caregivers offered brief descriptions of the physical impact of caregiving on their lives.

Caregiver #2 *"From the beginning, I gave my mom my life instead of giving myself my life."*

Caregiver #10 *"I have developed so many health problems. I developed asthma, acid reflex, pinched my siatic nerve, pneumonia, the lining of my stomach is all irritated, depression, and sleeping problems and I know every bit of it is stress from the way I have to live."*

Housing Modification Assistance Housing assistance for caregivers was classified either by changes that were necessary in the home or by need for information about nursing home placement. Six caregivers stated that modifications had to be made to the patient's home to provide a safer or adaptable environment. Home modifications made by caregivers

included hospital beds, toilet risers, tub/shower seats, ramps, knobs removed from stoves, added locks on doors, and door chimes added to discourage wandering.

Caregiver #10 *"I do hide all the keys and I keep the garage locked, so he can't go out into the garage. I don't move furniture anymore because it is so strange."*

Caregiver #4 *"We had to lock the doors. I put all of her clothes in the cedar chest and locked it. And we had taken away the knobs on the oven, and the sharp knives."*

Seven of the caregivers have had to seek assistance in gaining a greater insight into nursing home facilities. Some caregivers stated that plans were made by the patient in regard to nursing home placement. Other caregivers discussed the guilt and challenge that went along with the decision making process to place their loved one in a nursing home.

Caregiver #10 *"One thing that caregivers carry so much and no one has to give it to them, they do a very good job of giving it to themselves, and that is guilt."*

Caregiver #3 *"My mother put her application in (to a nursing home) probably 20 years ago. She said she would never live with any of the kids. She would rather be in a nursing home than dependent on the kids all the time."*

Caregiver #10 *"I was just recently asked what it would take to place him into a nursing home. The main thing is if he continues to be aggressive. I was close to it this fall. The other would be incontinence."*

Caregiver #5 *"I am concerned there isn't enough staff. It is the best place I could find and the staff is excellent but they need more trained people."*

Emotional Assistance All twelve caregivers discussed the impact that the patient's family had on the patient or their own life. Many caregivers were disappointed at the level of

care, support, or love that family members expressed. In fact, disappointment doesn't even begin to describe the emotion that these caregivers have felt.

Caregiver #3 *"I think the emotional strain was the most. Because family didn't, well my brother was, he knew what was happening, but I don't think he realized how confused she was getting all of the time. And the distance-wise, he wasn't as available. My sister was working at that time, she didn't want to take time off to do a lot of things."*

Caregiver #5 " I wish I had more support from my two daughters."

Caregiver #9 *"Much of the time I carried the load myself."*

Caregiver #2 *"I thought my brother would take my mom. I thought he would put in an appearance. Once he took her for three days. I had to call him to take her. I was angry at my brother because he didn't care for mother. He should have stood up and said, I'll help my brother."*

One caregiver was especially disappointed in the lack of assistance from friends. She explained that she and her husband were very proud people and how difficult it was to learn to ask for help. She seemed even more disappointed in those who offered assistance but did not back up their offer.

Caregiver #10 *"When you directly ask and you still don't get a response, that is what kills ya. When you are so desperate and you are willing to do anything to ask for help. We were proud people and learning to ask others for help was a big shocker for me. To get up the courage to ask and then get such a negative response or no response, it is crushing. That is when you feel most alone."*

She continued to say: *"On the other hand, those who do help, I will never never ever forget them. They are far and few between."*

Caregiver #10 *"Another very hard thing is when he was diagnosed so many people said if there is anything I can do just let me know. Ha, what a joke, nobody means it. I don't mean to be cruel, but it's true. Nobody means it. Everybody is afraid of Alzheimer's. After awhile I just quit asking for help." "I have three really best friends that have helped me through this. I didn't even have my kids support. That is where the support group has been vital. It was more frustrating that I didn't have my families support. You expect your kids to understand and to be there for ya and they just weren't. They are now."*

Eleven of the twelve caregivers had been to a support group of some kind at least once. Caregivers had this to say about their support group experience.

Caregiver #11 *"Support group for Alzheimer's patient in early stages might have helped."*

Caregiver #12 *"I attend a support group which is worth its weight in gold."*

Caregiver #10 *"My support group, just none of us can explain it. We all came together as strangers and came from different backgrounds but it is like we have known each other forever. We have this bond that absolutely cannot be broken."*

Caregiver #5 *"My support groups are wonderful. They are my social life, my friends. We truly understand and care for each other."*

Seven of the twelve caregivers have used adult day centers as a relief from caregiving. Only one of the caregivers was not able to continue use of the adult day center because of her husband's attitude about the center. This caregiver did propose the necessity of having day centers for adults that offer hours compatible with the workweek. Other caregivers highly recommended the use of adult day centers.

Caregiver #5 *"The adult day care was a life saver!"*

Caregiver #1 *"He regularly went to day-care on Tuesdays and Thursdays. And sometime he would ask me why he was going, and I said, well they are expecting you. It seemed he considered going to day care like a job that had to be done. That he left in the morning, went to his job, and came home about four in the afternoon, when the job was over."*

Spirituality Eight of the caregivers spoke about the role of the church or about spirituality during their interview. Three of the caregivers stated positive aspects about the church and church members, three caregivers had negative experiences with the church, and two were indifferent. The church and religion were very important to all eight of these caregivers. One caregiver expressed how proud she was that her husband was able to attend church until the day he died.

Caregiver #1 *"We always went to church, every Sunday. We went to church up until the day he died."*

Caregiver #3 *"I think the church has been her (patient) main support, her beliefs and her faith. I think we have all learned from her. We know she's in God's hands."*

Other caregivers still attended church but did not feel that they received support from the church community. Three caregivers shared a very emotional story about how church members, pastors, and ministers neglected to visit or care for their loved one.

Caregiver #10 *"I would encourage churches to be more supportive. I don't feel that the church gave me the support I needed. When I took him (her husband) to an adult day center and he hated it. So, I went to my pastor and said, I have to have help. The pastor sided with him and decided that he didn't need to go to the adult day center. I said, look I need help. I can't take this. The pastor's response was, you said your marriage vows, for*

better or for worse, until death do you part. You have had the better, this is the worst and it is your responsibility to take care of him."

Caregiver #3 *"She's had very little visitors from the church. I've been a little disappointed in the church. It would be nice if someone would make the effort to get to see her. And even now that she recognizes faces, rather she knows who they are, I think our minister could come over a little more often. I hate to downgrade him (the minister). From what I have seen he doesn't appear as supportive as I thought they would have been."*

Caregiver #9 *"I was disappointed in them, mainly in the people from church. I expected them to do much more than what they did. Many of these people had known her for years and when she died. I expected more from them."*

Despite these caregivers' experiences with the church many of them still had a strong faith. All but two of the eight caregivers considered themselves an active member of the church and a spiritual being before the diagnosis. These two caregivers shared this information about how their spirituality has helped them through their time as a caregiver.

Caregiver #10 *"No, before we married, I was raised in the church and he wasn't. So, once we were married, I stopped going because it was just too complicated. My faith is the only thing now that gets me through, it is the only thing that I can depend on. God is the only one that I can count on. My faith has grown leaps and bounds."*

Caregiver #10 *"This tragedy has brought me to God and what he teaches. That he is the only one we can count on in life."*

Caregiver #5 *"I'm not a religious person but now feel God teaching me and leading me. A profound experience."*

Caregiver Stress Surprisingly, only two caregivers out of the twelve actually used the term stress when discussing their role as a caregiver. Caregiver number ten described all of the medical problems that she has developed and assumes that most of these problems are due to stress. Caregiver number four stated it was stressful to watch her mother go downhill. However, other caregivers used a number of terms and phrases that could be labeled as stress. Caregivers used terms such as: worrying, can't deal with it, disappointed, overloaded, frustrated, and angry.

Caregiver #12 *"Besides worrying about my father, I also was managing mother."*

Caregiver #11 *"I have an understanding husband. I don't know if I could deal with this if I didn't."*

Caregiver #4 *"She wasn't like she had been, the loving mother. She is angry with us all of the time. Sometimes we (caregiver and husband) just had to get out."*

Caregiver #9 *"Much of the time I felt like I carried the load myself."*

Caregiver #6 *"I need to know how to handle his stubbornness. Do I get angry?"*

Caregiver's Satisfactions and Strengths

Through all of the disappointments, needs, and concerns, this researcher began to wonder if there were any satisfactions in caregiving or if caregivers were able to see their own strengths. Each caregiver was asked to express some of the satisfactions in caregiving or to explore their strengths as a caregiver.

Caregiver #10 *"Oh my. It has totally changed me. I am not the same person. This is one of the things that I was angry about in the beginning. I didn't have any dreams anymore. Number one is, my faith has grown so strong through all of this. Also, I don't live for*

tomorrow anymore. I don't live for things. It is the simple things in life that I now realize the value of. Going for a walk and looking at the stars and think this is a big world isn't it."

Caregiver #7 *"Really everything is positive about caregiving. She really entertains me. I enjoy it."*

Caregiver #8 *"I don't mind it (caregiving). There are times I don't enjoy it but I go to group and then I'd be okay."*

Caregiver #5 *"I have come through these nine years from anger and why me, poor me to becoming more caring, more compassionate, a truly different person. I have learned a lot. I have changed. I have changed, feeling a new purpose in my life."*

Caregiver #1 *"There were so many things to be thankful for, things could have been so much worse. We have a beautiful view here. I get the sunsets."*

Four of the caregivers were not as able to think of satisfactions in caregiving. These caregivers would say I don't know or I can't think of any right now. It was definitely a struggle for these caregivers to think of the better things or strengths in caregiving.

Meaning-Making

Throughout all twelve of the interviews so much information was offered. These caregivers were dedicated to sharing so much information that went beyond answering the researcher's questions. These details and descriptions seemed to coincide with what each particular caregiver believed to be the most important or most relevant to their experience. These details and description fit with Nadeau's (1998) definition of meaning-making. According to Nadeau, (1998) meaning is defined as

> "...the products of interactions with others and are influenced by the context in which they occur, including the influence of society, culture, and historical time (p.#14)."

Therefore, meaning-making in this study included caregivers' stories about how they were influenced by caregiving and by those around them.

Many of the caregivers tried to explain why they think they were given the role of caring for an Alzheimer's patient. Two caregivers shared caregiver number ten's explanation for the reason why they were given this challenge. Many times the caregivers would say, everything happens for a reason.

Caregiver #10 *"I am a firm believer that every bad thing that happens, something good comes out of it. I know that there is a reason for all of this. Most of the time it is, too difficult to see. It is so painful and it hurts so much."*

Caregiver #4 *"Well I say, that religion helps. And I think she'll still go to heaven despite her hates, hating us. And as I say, we go to church every Sunday for as long as I remember, and still do. I think that helps.*

Caregiver #10 *"I approach everything as what would he say if he were in good health. I got this advice from his doctor at the Mayo Clinic. It is one of the best pieces of advice that I have gotten. The only thing he has said, and this was at the beginning was, do what you have to do but please just promise me that you will take care of me. And I did. I didn't make any promises how. I didn't make any promises that I wouldn't put him in a nursing home. I promised him that I would do my very best to take care of him until the day he dies and I will. I will always take care of him."*

Caregivers would share what they believed to be the hardest part about caregiving. Two caregivers stated that the incontinence was the hardest thing to deal with. Two stated that each day was a 36-hour day. Others seemed to be most impacted emotionally.

Caregiver #9 *"I didn't want to admit it and I was in denial for a long time. It didn't seem possible that such a wonderful lady could have such a horrible thing happen to her. I kept hoping it was something else, not Alzheimer's."*

Caregiver #10 *"The hardest was giving up our dreams. When I heard the diagnosis, I just cried and cried. It was like the whole world stopped and we died right then, right that night. Every thing was over. The life that we had planned was gone, just that quick is was gone."*

Not only did each caregiver face some difficult struggles, one caregiver had expressed the sadness she felt when she had realized that the Alzheimer's patient no longer recognized her. Caregiver number ten had planned to take her husband to Las Vegas just one last time and out of the blue before the trip he stated that he was really looking forward to the trip. She said that after that comment he had asked her if she had ever been to Las Vegas.

Caregiver #10 *"That was the first time that I knew that he didn't have a clue who I was. He had no idea who I was. It was another slap in the face, just one more step. I really don't know if he recognizes me."*

Luckily most of the other caregivers did not or have not had to deal with the traumatic realization that their loved one no longer knew who they were. The three caregivers who had lost their loved one stated that they believed the patients still recognized them until the day they died. This statement itself represented meaning-making in how they had hoped that the patient had still recognized them regardless of the number of things that were no longer a part of their memory.

Seven of the twelve caregivers were interested in offering suggestions that may help future caregivers. It was emphasized by many caregivers how extremely difficult it is to be a

caregiver. However, specific suggestions were made by caregivers on how to best cope with their situation.

Caregiver #10 *"In the beginning, I couldn't read it (the 36-hour day). I still have not been able to read that book. I just can't get through it. It is too difficult. I can only read so much about tangles and plaques. Too much of it just depresses me. Get a support group, and if you don't like the first one you go to, go to another."*

Caregiver #11 *"Look for the simple pleasures. Importance of not postponing one's happiness."*

Caregiver #6 *"Do what you feel you can handle."*

Caregiver #7 *"Get with a group to reduce stress. After I came home from group I could come in and hug and kiss her (patient) and say, you wear a halo. Also, get a routine down."*

Many caregivers ended their interview by sharing meanings that included leaving a legacy about the Alzheimer's patient. Meaning-making was apparent for so many caregivers who wished to describe how they believed the Alzheimer's patient would want to be remembered

Caregiver #4 *"I suppose a loving mother, she loved the kids. She loved us, told us she loved us as kids, and would hug us, help us with homework if we needed it.*

Caregiver #10 *"Of course he would absolutely hate it if he knew some of the things he does and some of the things he says."*

Caregiver #10 *"I am sure that he would have lived his life differently if he would realized that he was going to end up like this. I don't think he would have worked as many*

hours. He wouldn't have put as much an emphasis on money. He kept wanting to save money for retirement. Now he won't even see retirement."

Caregiver #3 *"For her beliefs. Her love of Christ and always wanting to help other people. I think that would be the one thing that she would want to be remembered by."*

Caregiver #9 *"We have always been a very close and loving couple. She was still the same woman I married, only a little sicker."*

Summary

The information shared by the caregivers through the interview process developed into a grounded theory that included three components. The three components that became most apparent were: 1) the stages of caregiving, 2) the needs, struggles, and satisfactions of caregiving, and 3) meaning-making by caregivers. The stages of caregiving were in correspondence with patients in early-onset, early stage, middle stage, late stage, and those who recently have passed on from complications of Alzheimer's. The needs and struggles of caregiving included areas of financial, legal, medical, housing, emotional, spiritual, and caregiver stress. Caregivers also shared their strengths, satisfactions, and the meaning-making that goes along with caring for an Alzheimer's patient.

Through the interviews, similarities existed not only for patients who were currently in the same stage of the disease, but similarities also existed among the individuals who cared for these patients. Caregivers who cared for a patient in the early stage suggested that caregiving was not too difficult. Those with a patient in the middle stage seemed to be in the depths of emotional turmoil and feeling overwhelmed. Those who care for someone in the late stage were dealing with the numerous challenges that accompany caring for these patients, such as incontinence, and assisting with all of the daily activities. Finally, those

who had a loved one who was currently deceased felt the need to remember their loved one and recollect the history of the patient.

Caregivers were able to offer such in-depth information about specific needs that they had encountered when caring for an Alzheimer's patient. The caregivers' needs and struggles were either fulfilled or not fulfilled through the assistance of another. Caregivers were able to share how particular practitioners have been helpful and also suggested what has not been helpful.

Although somewhat more difficult, caregivers were able to share some of the strengths or satisfactions in caring for someone with Alzheimer's. Unfortunately, some of the caregivers had been affected so negatively that the strengths of caring went unnoticed.

Through the interviews, each caregiver shared stories about the patient or how they would hope that the patient would be remembered. These stories were labeled as meaning-making and describe the meanings that each caregiver attributed to his or her experience. The meaning-making included caregivers' beliefs of how the patient would make sense of the disease, what would be helpful to other caregivers, and how the patient would want to be remembered.

Quantitative Results

After the conclusion of all twelve interviews, enough information had been gathered that a saturation point had been evident at each stage of caregiving, in caregiver needs, struggles, and satisfactions, and in meaning-making by the caregivers. Thus, a questionnaire was developed from the domains and categories that were most pertinent in the interview and first given to the same caregivers who had completed the interview, with the exception of the three who had lost their loved ones. The questionnaire was developed in hopes of gaining a

greater understanding for what assistance current caregivers needed. Most of the questions applied only to current caregiver status. Replies from the pilot study of these nine respondents were examined first to search for errors or confusion in the questionnaire. All nine of the respondents completed the questionnaire and noted that two minor changes would have been helpful. One change was to add the words "current" and "condition" to the description of the Alzheimer's patient on page six of the questionnaire. The second change was to invite caregivers the opportunity to include additional thoughts or comments if they wished to do so. A comment was added to the bottom of page 7 that read: "Feel free to add comment on the back of this form." Because all nine of the caregivers had responded to the description of the Alzheimer's patient on page six of the questionnaire in their current condition, the changes were considered minor and these results were added to subsequent results from caregivers who did not participate in the interview process.

Results from the questionnaire follow a format that coincided with the outcome from the interview process. Respondents were asked first to answer a number of demographic questions. Subsequent sections included a description of: 1) the Alzheimer's patient, 2) how the caregiver has felt over the past week, 3) how the caregiver would describe the Alzheimer's patient's physician, 4) the patient's doctor, familial support, non-familial support, legal assistance, church community, and the Alzheimer's patient's current condition, and 5) open-ended questions about the caregiver's experience in caring for an Alzheimer's patient.

Frequencies

Frequencies and percentages for the demographics from the quantitative portion of this study are presented in Table 1 and Table 2. The demographics in Table 1 are presented by gender of the caregiver.

Demographics

There were five male caregivers and thirty female caregivers included in this study. With respect to caregivers' age, two of the females were age 36-45. Furthermore, one male and seven of the females were age 46-55 and one male and eight females were 56-65. In addition, two male and seven females were age 66-75, with one male and six females aged 75 or older.

Caregivers were most likely to live in a city of 50,000 people. Three males and 15 females came from this size of city. Furthermore, two male and eleven females were from towns with populations of less than 15,000 people and four females came from towns with 20,000-50,000 people.

Male caregivers were very educated. As one had at least some college, three had four years of college, and one had his Ph.D. Female caregivers also tended to be well-educated. Only one caregiver had less than a high school education. Twelve females had completed high school, seven had completed at least some college, eight had four years of college, and two had completed their Master's degree.

Of the male respondents, three cared for their spouse, one cared for his father, and one cared for his mother. On the other hand, fourteen females cared for their spouse, eleven cared for their mother, one cared for her sister, and four cared for a mother-in-law, aunt, or friend.

Table 1. Percentages and (frequencies) for study sample demographics, by gender of caregiver.

Demographics	Men %	(n)	Women %	(n)
Age				
36-45	0%	(00)	6.7%	(02)
46-55	20%	(01)	23.3%	(07)
56-65	20%	(01)	26.7%	(08)
66-75	40%	(02)	23.3%	(07)
75+	20%	(01)	20.0%	(06)
Town size of Residence				
Less than 15,000	40%	(02)	36.7%	(11)
20,000-50,000	0%	(00)	13.3%	(04)
More than 50,000	60%	(03)	50.0%	(15)
Education Level				
Less than high school	0%	(00)	3.3%	(01)
High school diploma	0%	(00)	40.0%	(12)
Some/2 yrs of college	20%	(01)	23.3%	(07)
4 years of college	60%	(03)	26.7%	(08)
Master's	0%	(00)	6.7%	(02)
Ph.D.	20%	(01)	0%	(00)
Patient's Relationship to Caregiver				
Spouse	60%	(03)	46.7%	(14)
Father	20%	(01)	0%	(00)
Mother	20%	(01)	36.7%	(11)
Sister	0%	(00)	3.3%	(01)
Other (mother-in-law)	0%	(00)	13.3%	(04)
Live with Patient				
Yes	40%	(02)	46.7%	(14)
No	60%	(03)	53.3%	(16)
Caregiver Work Outside of Home				
Yes	60%	(03)	43.3%	(13)
No	40%	(02)	56.7%	(17)

Note: N=35

Table 1. (continued)

Demographics	Men %	(n)	Women %	(n)
Hours Spent Caregiving/day				
1-5 hours/day	40%	(02)	56.7%	(17)
6-10 hours/day	0%	(00)	6.7%	(02)
11-15 hours/day	0%	(00)	3.3%	(01)
16-20 hours/day	0%	(00)	13.3%	(04)
21-24 hours/day	60%	(03)	20.0%	(06)
Number of hours worked outside home				
0 hours	40%	(02)	60.0%	(18)
9 hours	0%	(00)	3.3%	(01)
12 hours	0%	(00)	3.3%	(01)
20 hours	0%	(00)	6.7%	(02)
30 hours	20%	(01)	3.3%	(01)
35 hours	0%	(00)	3.3%	(01)
40 hours	20%	(01)	20.0%	(06)
40+ hours	20%	(01)	0%	(00)
Stage of patient cared for				
Early	40%	(02)	23.3%	(07)
Moderate	40%	(02)	46.7%	(14)
Late	10%	(01)	30.0%	(09)
Questionnaire collected from				
Support group	40%	(02)	43.3%	(13)
Adult day center	40%	(02)	26.7%	(08)
Interview	20%	(01)	26.7%	(08)
Community	0%	(00)	3.3%	(01)

Two of the male caregivers and fourteen of the female caregivers lived with the Alzheimer's patient. The remaining three male caregivers and sixteen female caregivers did not live with the patient.

Unfortunately, many of the caregivers worked outside of the home, in addition to caregiving. Three males and thirteen females worked outside of the home. The males

worked 30, 40, and 40+ hours per week. The females worked 9 to 40 hours per week. The majority of females (6) who work outside the home work forty hours a week.

Caregivers dedicated a range of hours in caring for the Alzheimer's patient. Forty percent of the males cared for the patient one to five hours per day and 60% cared for the patient 21 to 24 hours per day. Of the females, 17 cared for the Alzheimer's patient one to five hours per day, two cared for the patient six to ten hours per day, one cared for the patient 11 to 15 hours a day, four cared for the patient 16 to 20 hours per day, and six cared for the patient 21 to 24 hours per day.

Alzheimer's patients were categorized into early, moderate, or late stage of the disease process. Two of the male caregivers and seven of the female caregivers cared for a patient in the early stage of the disease. Furthermore, two of the males and fourteen of the females caregivers cared for a patient in the moderate stage, and one male and nine females cared for a patient in the last stage of the disease.

The questionnaires were collected at support group meetings from two males and thirteen females. Questionnaires were also collected from two males and eight females who took the patient to an adult day center, and one female from the community participated who learned by word of mouth. Eight females and one male who participated in the interview process also participated in the quantitative portion of this study.

The demographics of the Alzheimer's patient are presented in Table 2. Demographics of the patient included age, level of education, stage in the disease process, size of town that the patient lived in, and whether the patient lived with the caregiver.

There were fifteen male patients and twenty female patients included in the quantitative portion of this study. One male patient was age 46 to 55, one male was age 56 to

Table 2. Percentages and (frequencies) for study sample demographics, by gender of patient.

Demographics	Men % (n)	Women % (n)
Age		
46-55	6.7% (01)	0% (00)
56-65	6.7% (01)	5.0% (01)
66-75	33.3% (05)	20.0% (04)
75+	53.3% (08)	75.0% (15)
Size town of residence		
Less than 15,000	46.7% (07)	30.0% (06)
20,000-50,000	6.7% (01)	15.0% (03)
more than 50,000	46.7% (07)	55.0% (11)
Education level		
Less than high school	6.7% (01)	20.0% (04)
High school diploma	53.3% (08)	40.0% (08)
Some/2 yrs of college	20.0% (03)	20.0% (04)
4 years of college	13.7% (02)	20.0% (04)
Ph.D.	6.7% (01)	0% (00)
Lives with caregiver		
Yes	73.3% (11)	25.0% (05)
No	26.7% (04)	75.0% (15)
Stage of disease		
Early	20.0% (03)	30.0% (06)
Moderate	40.0% (06)	50.0% (10)
Late	20.0% (06)	20.0% (04)

Note: N=35

65, five males were 66 to 75 and eight were 75 or older. However, one female was age 56 to 65, four females were age 66 to 75, and fifteen females were 75 or older.

Seven males and eleven females were from a city of 50,000 people or more. Only seven males and six females were from communities of less than 15,000 people, and one male and three females were from cities with populations between 20,000 and 50,000 people.

In response to education, one male had less than a high school diploma, eight males had a high school diploma, three had completed at least some college, two had completed

four years of college, and one had his Ph.D. On the other hand, four females had less than a high school diploma, eight had a high school diploma, four had completed at least some college, and four had completed four years of college.

Of the male patients, three were considered to be in the early stage of the disease process, six were in the moderate stage, and six were in the late stage. Furthermore, six of the females were in the early stage, ten were in the moderate stage, and four were in the late stages. In addition eleven of the males and five of the females lived with their caregivers.

Alzheimer's Patient Behaviors Checklist

Table 3 presents frequencies and percentages for the Alzheimer's patients' current behaviors. The results of the patients' behaviors are clustered by the stage of disease that the caregiver believed best described the patient's current condition.

The majority of the caregivers who cared for someone in the early stage (72.8%), middle stage (100%), and late stage (70.0%) stated that the patient had trouble remembering recent events daily or more often. However, patients in the early stage had less of a problem remembering past events. Approximately 33.3% of the early stage patients had trouble remembering significant past events recently but not in the week prior to the completion of the questionnaire. Those in the middle stage (68.8%) and late stage (60%) were more likely to have troubles remembering significant past events on a daily basis or more often.

Early stage patients were also less likely to mix up past and present. Nearly 33.3% of the patients in the early stage had not mixed up past and present in the last three months. However, those in the middle stage (56.3%) and those in the late stage (70%) mixed up the past and present on a daily basis or more often.

Table 3. Percentages and (frequencies) for the Alzheimer's Patient Behavior Checklist, by stage in the disease process.

Variable	Early % (n)	Moderate % (n)	Late % (n)
Trouble remembering recent events			
Never occurred	11.1% (01)	0% (00)	0% (00)
1 to 2 times in past week	11.1% (01)	0% (00)	0% (00)
Occurs daily	72.8% (07)	100% (16)	70.0% (07)
Would occur w/o supervision	0% (00)	0% (00)	30.0% (03)
Trouble remembering past events			
Never occurred	11.1% (01)	0% (00)	0% (00)
Occurred recently, not in last week	33.3% (03)	12.5% (02)	0% (00)
1 to 2 times in past week	0% (00)	0% (00)	10.0% (01)
3 to 6 times in past week	11.1% (01)	18.8% (03)	30.0% (03)
Occurs daily	33.3% (03)	68.8% (11)	40.0% (04)
Would occur w/o supervision	11.1% (01)	0% (00)	20.0% (02)
Mixing up past and present			
Never occurred	11.1% (01)	12.5% (02)	0% (00)
Occurred but not in past 3 months	33.3% (03)	0% (00)	0% (00)
Occurred recently, not in last week	0% (00)	6.3% (01)	0% (00)
1 to 2 times in past week	11.1% (01)	12.5% (02)	10.0% (01)
3 to 6 times in past week	11.1% (01)	12.5% (02)	20.0% (02)
Occurs daily	33.3% (03)	50.0% (08)	40.0% (04)
Would occur w/o supervision	0% (00)	6.3% (01)	30.0% (03)
Losing or misplacing things			
Occurred but not in past 3 months	11.1% (01)	0% (00)	0% (00)
Occurred recently, not in last week	11.1% (01)	6.3% (01)	10.0% (01)
1 to 2 times in past week	11.1% (01)	0% (00)	0% (00)
3 to 6 times in past week	0% (00)	12.5% (02)	10.0% (01)
Occurs daily	44.4% (04)	68.8% (11)	40.0% (04)
Would occur w/o supervision	22.2% (02)	12.5% (02)	40.0% (04)

Note: N=35

Table 3. (continued)

Variable	Early % (n)	Moderate % (n)	Late % (n)
Wandering or getting lost			
Never occurred	44.4% (04)	18.8% (03)	20.0% (02)
Occurred but not in past 3 months	0% (00)	12.5% (02)	20.0% (02)
Occurred recently, not in last week	0% (00)	12.5% (02)	0% (00)
1 to 2 times in past week	11.1% (01)	6.3% (01)	0% (00)
3 to 6 times in past week	11.1% (01)	6.3% (01)	10.0% (01)
Occurs daily	11.1% (01)	6.3% (01)	10.0% (01)
Would occur w/o supervision	22.2% (02)	37.5% (06)	40.0% (04)
Not recognizing familiar places			
Never occurred	33.3% (03)	12.5% (02)	10.0% (01)
Occurred recently, not in last week	11.1% (01)	12.5% (02)	0% (00)
1 to 2 times in past week	44.4% (04)	12.5% (02)	0% (00)
3 to 6 times in past week	0% (00)	0% (00)	10.0% (00)
Occurs daily	11.1% (01)	37.5% (06)	40.0% (04)
Would occur w/o supervision	0% (00)	25.0% (04)	40.0% (04)
Unable to start daily activities			
Never occurred	44.4% (04)	31.3% (05)	0% (00)
Occurred recently, not in last week	11.1% (01)	6.3% (01)	0% (00)
1 to 2 times in past week	11.1% (01)	12.5% (02)	10.0% (01)
3 to 6 times in past week	11.1% (01)	6.3% (01)	0% (00)
Occurs daily	11.1% (01)	31.3% (05)	60.0% (06)
Would occur w/o supervision	11.1% (01)	12.5% (02)	30.0% (03)
Constantly restless			
Never occurred	0% (00)	12.5% (02)	10.0% (01)
Occurred but not in past 3 months	22.2% (02)	6.3% (01)	10.0% (01)
Occurred recently, not in last week	11.1% (01)	12.5% (02)	20.0% (02)
1 to 2 times in past week	11.1% (01)	0% (00)	0% (00)
3 to 6 times in past week	44.4% (03)	31.3% (05)	0% (00)
Occurs daily	11.1% (01)	31.3% (05)	30.0% (03)
Would occur w/o supervision	0% (00)	6.3% (01)	30.0% (03)

Table 3. (continued)

Variable	Early % (n)	Moderate % (n)	Late % (n)
Talking little or not at all			
Never occurred	44.4% (04)	18.8% (03)	10.0% (01)
Occurred but not in past 3 months	11.1% (01)	6.3% (01)	0% (00)
Occurred recently, not in last week	11.1% (01)	18.8% (03)	10.0% (01)
1 to 2 times in past week	11.1% (01)	6.3% (01)	0% (00)
3 to 6 times in past week	22.2% (02)	0% (00)	30.0% (03)
Occurs daily	0% (00)	50.0% (08)	30.0% (03)
Would occur w/o supervision	0% (00)	0% (00)	10.0% (01)
Being suspicious or accusative			
Never occurred	22.2% (02)	37.5% (06)	30.0% (03)
Occurred but not in past 3 months	33.3% (03)	25.0% (04)	10.0% (01)
Occurred recently, not in last week	11.1% (01)	18.8% (03)	10.0% (01)
1 to 2 times in past week	22.2% (02)	0% (00)	10.0% (01)
3 to 6 times in past week	0% (00)	12.5% (02)	30.0% (03)
Occurs daily	11.1% (01)	6.3% (01)	0% (00)
Would occur w/o supervision	0% (00)	0% (00)	10.0% (01)
Strikes out or tries to hit			
Never occurred	77.8% (07)	62.5% (10)	10.0% (01)
Occurred but not in past 3 months	11.1% (01)	6.3% (01)	30.0% (01)
Occurred recently, not in last week	11.1% (01)	25.0% (04)	30.0% (03)
3 to 6 times in past week	0% (00)	0% (00)	20.0% (02)
Occurs daily	0% (00)	6.3% (01)	0% (00)
Would occur w/o supervision	0% (00)	0% (00)	20.0% (02)
Appears sad or depressed			
Never occurred	11.1% (01)	12.5% (02)	10.0% (01)
Occurred but not in past 3 months	11.1% (01)	12.5% (02)	10.0% (01)
Occurred recently, not in last week	22.2% (02)	12.5% (02)	0% (00)
1 to 2 times in past week	22.2% (02)	6.3% (01)	10.0% (01)
3 to 6 times in past week	11.1% (01)	6.3% (01)	10.0% (01)
Occurs daily	22.2% (02)	37.5% (06)	40.0% (04)
Would occur w/o supervision	0% (00)	12.5% (02)	20.0% (02)

The majority of caregivers stated that the patient that they cared for had a tendency to lose or misplace things. Approximately 66.6% of those in the early stage, 81.3% in the middle stage, and 80% in the late stage lose or misplace things on a daily basis or more often.

Nearly 44% of the caregivers of those in the early stages stated that the patient had never wandered or got lost. However, almost 44.8% of those in the middle stage and 50% of those in the late stage stated that the patient would wander if he or she was not supervised.

Several of the caregivers stated that the patient had difficulty recognizing familiar places. Approximately 57% of those considered in the early stage had this difficulty one to two times in the past week. In addition, 62.5% of those considered in the middle stage and 80% considered to be in the late stage of the disease process have difficulty recognizing a familiar place daily or more often.

Those in the early stage of the disease didn't have as many difficulties as those in the late stage with being able to start their daily activities by themselves. Forty-four percent of those in the early stage had never had difficulties starting daily activities. On the other hand, 43.8% of those in the middle stage and 90% of those in the late stage were unable to start their daily activities daily or more often.

Almost half (44.4%) of the patients in early stages were restless one to two times in the last week. Approximately 31.3% of those in the middle stage were restless three to six times in the past week and 37.6% in the middle stage and 60% in the late stage had been restless daily or more often. A large number of patients in the middle stage (50%) and 40% of those in the late stage talk little or not at all on a daily basis.

Suspicious behavior did not occur on a more frequent basis due to the stage of the disease. Depression affected 22.2% of those in the early stage, 43.8% of those in the middle

stage, and 60% of those in the last stage on a daily basis or more. The majority of those in the early stage (77.8%) and in the middle stage (62.5%) had not ever tried to hit or strike out. However, 30% of those in the late stage had tried to strike out recently but not in the past week.

Feelings of Caregiver Assessment

The third set of questions included an assessment of how the caregiver had felt over the past week. Results of the Feelings of Caregiver Assessment are provided in Table 4. The results were offered by caregivers but are categorized by the stage of the disease process that the patient whom they care for is currently in.

Approximately 33.3 % of the caregivers with a patient in the early stage of the disease process mentioned that they look forward to things as much as they used to most of the time, while 55.6% mentioned that they sometimes look forward to things as much as they used to. Furthermore, 43.8% of the caregivers with a patient in the moderate stage stated that they look forward to things as much as they used to and 43.8% responded with sometimes. Those caregivers who had a patient in the late stages were more likely to respond sometimes (50%) or never (30%) look forward to things as much as they used to.

In response to sleeping well, approximately 66.7% of those who cared for someone in the early stage, 56.3% of those who cared for someone in the moderate stage, and 10% of those who cared for someone in the late stage of the disease mentioned that they sleep well most of the time. Those who cared for someone in the middle stage (25%) and late stage (80%) were likely to say that they sometimes sleep very well. However, 18.8% of those who cared for someone in the middle stage stated that they never sleep very well.

Table 4. Percentages and (frequencies) from the Feeling of Caregiver Assessment, by stage in the disease process.

Variable	Early % (n)	Moderate % (n)	Late % (n)
Caregiver looks forward to things			
Most of the time	33.3% (03)	43.8% (07)	20.0% (02)
Sometimes	53.6% (05)	43.8% (07)	50.0% (05)
Never	11.1% (01)	14.3% (02)	30.0% (03)
Caregiver sleeps very well			
Most of the time	66.7% (06)	56.3% (09)	10.0% (01)
Sometimes	22.2% (02)	25.0% (04)	80.0% (08)
Never	11.1% (01)	18.3% (03)	10.0% (01)
Caregiver feels like crying			
Most of the time	0% (00)	0% (00)	30.0% (03)
Sometimes	55.6% (05)	81.3% (13)	70.0% (07)
Never	44.4% (04)	18.3% (03)	0% (00)
Caregiver feel like running away			
Most of the time	0% (00)	0% (00)	10.0% (01)
Sometimes	33.3% (03)	37.5% (06)	30.0% (03)
Never	66.7% (06)	62.5% (10)	60.0% (06)
Caregiver has lots of energy			
Most of the time	55.6% (05)	37.5% (06)	20.0% (02)
Sometimes	33.3% (03)	50.0% (08)	40.0% (04)
Never	11.1% (01)	12.5% (02)	40.0% (04)
Caregiver feels very lonely			
Most of the time	0% (00)	25.0% (04)	30.0% (03)
Sometimes	66.7% (06)	50.0% (08)	50.0% (05)
Never	33.3% (03)	25.0% (04)	20.0% (02)
Caregiver feels very bored			
Most of the time	0% (00)	6.3% (01)	10.0% (01)
Sometimes	33.3% (03)	37.5% (06)	50.0% (05)
Never	66.7% (06)	56.3% (09)	40.0% (04)

Note: N=35

The majority of caregivers with patients in the early (55.6%), moderate (81.3%), and late (70%) stages stated that sometimes they feel like crying. In addition, 33.3% of those with a patient in the early stage, 37.5% with some in the middle stage, and 30% in the late stage stated that they sometimes feel like running away.

The majority of caregivers caring for someone in the early stage (55.6%) of the disease stated that they had lots of energy most of time, compared to 37.5% caring for someone in the middle stage, and 20% caring for someone in the late stage. Caregivers with someone in the moderate stage were most likely to report that they sometimes had lots of energy (50%) and those with someone the last stage were most likely to state that they never had lots of energy (40%).

Caregivers with someone in the early (33.3%), middle (37.5%), and late (50%) stages were likely to state that they sometimes feel very lonely. Not surprising, 66.7% of those with a patient in the early stage, 56.3% with a patient in the moderate stage, and 40% with a patient in the late stage stated that they never felt bored.

Attitude About Doctor Evaluation

When assessing trust in physicians, male and female caregivers were likely to believe that the patient's doctor cared about them as a person (Table 5). However, four female caregivers did not believe that the doctor cared for them and nine females were neutral. In addition, the majority of male (100%) and female (66.6%) caregivers believed that the doctor cared for the Alzheimer's patient as a person. Five of the female caregivers did not believe that the doctor cared for the patient and six caregivers were neutral.

Table 5. Percentages and (frequencies) for the Attitude About Doctor Evaluation, by gender of the caregiver.

Variables	Men % (n)	Women % (n)
Doubt doctor cares about caregiver		
Strongly Agree	0% (00)	6.7% (02)
Agree	0% (00)	6.7% (02)
Neutral	0% (00)	30.0% (09)
Disagree	40% (02)	23.3% (07)
Strongly Disagree	60% (03)	33.3% (10)
Doubt doctor cares about patient		
Strongly Agree	0% (00)	6.7% (02)
Agree	0% (00)	10.0% (03)
Neutral	0% (00)	20.0% (06)
Disagree	40% (02)	33.3% (10)
Strongly Disagree	60% (03)	30.0% (09)
Doctor says something, must be true		
Strongly Agree	0% (00)	6.7% (02)
Agree	60% (03)	30.0% (09)
Neutral	40% (02)	33.3% (10)
Disagree	0% (00)	20.0% (06)
Strongly Disagree	0% (00)	10.0% (03)
Doctor doesn't do everything that could be done for patient		
Strongly Agree	0% (00)	13.3% (04)
Agree	20% (01)	23.3% (07)
Neutral	0% (00)	13.3% (04)
Disagree	60% (03)	33.3% (10)
Strongly Disagree	20% (01)	16.7% (05)
Doctor is Alzheimer's expert		
Strongly Agree	20% (01)	0% (00)
Agree	0% (00)	6.7% (02)
Neutral	60% (03)	33.3% (10)
Disagree	0% (00)	36.7% (11)
Strongly Disagree	20% (01)	23.3% (07)

Note: N=35

Table 5. (continued).

Variables	Men % (n)	Women % (n)
Doctor told caregiver how to care for patient		
Strongly Agree	0% (00)	3.3% (01)
Agree	40% (02)	13.3% (04)
Neutral	40% (02)	26.7% (08)
Disagree	20% (01)	30.0% (09)
Strongly Disagree	0% (00)	26.7% (08)
Distrust doctor's opinion and like second opinion		
Strongly Agree	0% (00)	10.0% (03)
Agree	0% (00)	13.3% (04)
Neutral	60% (03)	26.7% (08)
Disagree	40% (02)	33.3% (10)
Strongly Disagree	0% (00)	16.7% (05)

Caregivers were asked if the doctor told them something, whether they thought it was true. Sixty percent of the male caregivers agreed with this statement. On the other hand, 36.7% of the females agreed and 30.0% disagreed. Approximately 33% of the female caregivers responded neutrally.

When asked if the patient's doctor did everything he or she could for the patient, 80% of the male caregivers and 50% of the females stated that they agreed or strongly agreed with the statement. However, 46.6% of the female caregivers and 20% of the male caregivers did not believe that the doctor did everything he or she could. Furthermore, only 20% of the males and 6.7% of the females considered the patient's doctor an expert in taking care of Alzheimer's patient.

Finally, 40% of the male caregivers and 16.6% of the female caregivers suggested that the patient's doctor gave them information about how to care for an Alzheimer's patient.

Furthermore, 23.6% of the female caregivers sometimes distrust the doctor's opinion and would like a second opinion. Sixty percent of the males and 26.7% of the females responded neutrally.

Evaluation of Support System Checklist

Caregivers were provided with fifteen descriptors and were asked if they did or did not characterize the Alzheimer's patients' doctor, family members, non-family members, lawyer, church community, and the Alzheimer's patient's current condition. The descriptors that were most and least likely to be used by caregivers are provided below, additional frequencies can be found in Appendix G.

Caregivers were most likely to describe the patient's doctor as kind (85.7%), friendly (88.6%), and helpful (77.1%). Caregivers were least likely to describe the doctor as hypocritical (2.9%), phony (0%), and dishonest (0%). Caregivers typically described the patient's familial support as kind (82.9%), trustworthy (77.1%), and easy to get along with (74.3%). Caregivers were least likely to describe familial support as phony (5.7%) or dishonest (0%).

Non-familial caregivers were described as kind (85.7%), friendly (88.6%), helpful (80%), and easy to get along with (80%). Non-familial support was less likely to be phony (5.7%), or dishonest (2.9%).

Interestingly, legal support and church community support received the lowest percentages of the more desirable characteristics. Caregivers stated that lawyers were intelligent (57.1%), knowledgeable (51.4%), and helpful (57.1%). Lawyers were not described as hypocritical (2.9%), phony (2.9%), or dishonest (2.9%). In addition, church

communities were described as kind (65.7%) and friendly (60%) and less likely to be described as phony (5.7 %), or dishonest (2.9%).

Finally, the caregiver described the Alzheimer's patient in his or her current condition as kind (68.6%), friendly (65.7%), likable (62.9%), and loving (68.6%). Alzheimer's patients typically were not described as hypocritical (5.7%), phony (2.9%), or dishonest (0%).

In The Words of The Caregiver

Table 6 includes some additional information from close-ended questions asked of the caregivers. All of the male caregivers and fourteen of the thirty female caregivers made home modifications to the house in order to accommodate the Alzheimer's patient. More than half of the female caregivers (70%) and male caregivers (60%) attended Alzheimer's support groups. Furthermore, 60% of the male caregivers and 36.6% of the female caregivers took advantage of respite options.

Table 6. Percentages and (frequencies) of open-ended questions, by gender of the caregiver and patient's stage in the disease process.

	Men			Women		
	Early	Moderate	Late	Early	Moderate	Late
Variable	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)
Home Modification						
Present	100% (02)	100% (02)	100% (01)	14.3% (01)	42.9% (06)	77.8% (07)
Not Present	0% (00)	0% (00)	0% (00)	85.7% (06)	57.1% (08)	22.2% (02)
Attend SupportGroup						
Yes	50% (01)	50% (01)	100% (01)	85.7% (06)	64.3% (09)	66.7% (06)
No	50% (01)	50% (01)	0% (00)	14.3% (01)	35.7% (05)	33.3% (03)
Utilize Respite						
Yes	50% (01)	100% (02)	0% (00)	14.3% (01)	50.0% (07)	33.3% (03)
No	50% (01)	0% (00)	100% (01)	85.7% (06)	50.0% (07)	66.7% (06)

N=35

Caregivers had the opportunity to respond to five open-ended questions, in addition to offering personal experiences of caregiving. Caregivers were first asked to list any areas that they wished they had more help with. Caregivers responded with the following remarks:

- Someone to help me clean the house, such as family.
- Legal and financial questions, I hear a lot of conflicting advice and options. I wish I had support from my two daughters.
- Getting her ready in the morning. Weekends when I want to do things outside or in a different part of the house.
- I have no help from my brother and his wife or children.
- Someone to stay with him once in awhile so I could have more free time.
- That the nursing home where she lives would train all the staff about the palliative models of caring for Alzheimer's and to understand more about the disease.
- Taken away from the home on occasion, such as rides, walks, restaurants
- Overnight help so that I might take brief trips.
- All day daycare in rural areas and respite for those in rural communities
- I need to talk more with other caregivers.
- More cooperation with family members.
- Help/support outside of work hours.
- Investment decisions, care options, when to go to a nursing home.
- Help from sister.
- Throughout illness lacked support from adult children.

Caregivers were then asked to state any modifications that needed to be made to the

home to accommodate the Alzheimer's patient. Home modifications included:

- Dead bolt locks on front and rear doors, installed a gate over open stairway.
- Knobs on stove taken off, alarm on door, adjust and add hand held shower head.
- Hid scissors and the stove was disconnected for awhile.
- Modified door locks to prevent leaving rooms and the home.
- Disconnected stove, disconnected water softener, removed electric blanket.
- Plastic handles on doors.
- Moved to a small house, all rooms are on one floor.
- Leave doors unlocked.
- Door knobs removed, doors and locks added to restrict her activity, a porta-pot, considering lock on refrigerator.
- Hospital bed, toilet riser, tub/shower seat, and looking into a ramp.

Caregivers were also asked to comment on what would have made their caregiving experience easier on them. Responses included:

- Getting sister to realize what was happening.
- Support from employer, community awareness, more services for long distance caregivers.
- That friends could be more comfortable with the situation, rather than avoiding us.
- Having someone to come to her home to take care of her.
- I wish I would have joined a support group sooner.
- Educated help for in the home, that is affordable.

- Getting more help from family members
- Better understanding and support from family.
- Doctor could have recommended that I have my mother evaluated or suggested that I look for information rather than just accepting her symptoms as part of aging process.
- That her family be more understanding.

Caregivers were asked if they could share some of their strengths, happy times, or satisfactions in caring for an Alzheimer's patient. Caregivers had these positive comments to share:

- Have them recall the past, when they were young. Repeat I love you several times a day.
- Funny actions or statements by patient that remind us to maintain a sense of humor.
- Every once in awhile a feeling of closeness. A great appreciation for my family.
- Knowing I can still take care of her at home.
- She lets me help her and seems to appreciate me.
- The happy times are when we dance together and he's smiling, this makes my day worthwhile.
- It is a whole new phase in our relationship-a challenge for all. We have found a new closeness through therapeutic massage.
- Their memory loss can be a blessing at times.
- Music has been very helpful. Family visits are great.

- This tragedy has brought me to God and what he teaches.
- It has made me more patient. I look for simple pleasures now everyday.
- Sense of satisfaction in helping.
- She expresses appreciation for our help.
- Taking each day at a time.
- Seeing that my mother is secure and responsive to my care is all the reward I need.
- Knowing she is capable of feeding herself.
- Knowing the kind and loving husband, my husband was in his health

Finally, caregivers had the opportunity to share any additional comments that would better help the researcher and other caregivers understand the needs, concerns, and satisfactions in caring for an Alzheimer's patient. These were some of the statements provided by the caregivers:

- Relating to other caregivers and having a strong faith in God has been what has sustained me through this most difficult time in my life.
- You have to want to.
- Frustrations at not being able to take care of my needs. Anger at seeing daily decline and inability to function. Worry about when to put in nursing home and financial aspects and wear on my home.
- Some need for care options in small communities.
- At this point, I don't know. I just know that I am a different person and I do what I have to do and one day I will understand what this is all about.

- A daily routine is important with as much stimulation during the day as possible. Also smile if it kills you to avoid a temper tantrum.
- The education is what helps me cope and feel I am doing the best I can for her.
- The stress, most family and friends just disappear, because you are so restricted in your activities. Depression and loneliness.

Factor Analysis

A factor analysis was conducted with the variables from the four main sections utilized in the questionnaire. From this factor analysis four factors were established that coincided with the measure utilized in the questionnaire and also with the domains that were highlighted from the qualitative portion of the study. These factors were labeled: 1) behaviors of the Alzheimer's patient, 2) caregivers' feelings, 3) trust in physician, and 4) support system evaluation. The factor loadings within each factor ranged from .125 to .853. The majority of factor loadings were above .6 within each factor. Table 7 includes a comparison of the quantitative results from the factor analysis and the breakdown of domains of meaning from the qualitative portion.

The factor loadings from the questionnaire mirror the outcomes from the domain analysis of the interview process. The domain titled, stages of caregiving described the correlation of stage of caregiving with the behaviors of the Alzheimer's patient, as supported through the factor one loading. The domain titled, caregiver's needs, struggles, and satisfactions included clusters that detailed caregiver's feelings, caregiver's trust in physicians, and caregiver's evaluation of their support system.

Table 7. Factor loadings and level of agreement with domains of meaning.

Factor Loadings	Domain of Meaning
Factor 1 Behaviors of the Alzheimer's Patient	Stages of Caregiving
Factor 2 Caregiver's Feelings	Caregivers' Needs, Struggles and Satisfactions
Factor 3 Trust in Physician	Caregivers' Needs, Struggles and Satisfactions
Factor 4 Support System Evaluation	Caregivers' Needs, Struggles and Satisfactions

In addition, open-ended questions were included in the quantitative and qualitative portions that resulted in an overlap in outcome results. For example, the domain analysis included caregivers' strengths and meaning-making as a domain. Caregivers' strengths were shared by caregivers who participated in the interview process and also by caregivers who answered an open-ended question on the questionnaire that allowed them to reflect on their strengths. Strengths mentioned by the caregivers in both portions included how this role had brought them closer to God, closer to the patient, or allowed them to appreciate the smaller things in life.

Meaning-making was also provided by the participants in the quantitative portion through additional comments and journals attached to the questionnaire. Meaning-making in both the qualitative and quantitative portions included statements about caregiver's making sense of their role, how they are able to help future caregivers, and how they believe that the patient would want to be remembered.

Analysis of Variance

In addition to frequencies, crosstabulations, and factor analysis, analysis of variance tests were conducted on with several dependent variables with caregiver's gender as the independent variable. In regard to the small sample size from this study, this analysis of variance results must be considered preliminary in nature. The only significant outcome was with presence of home modification ($F=5.39$, $p<.05$). The variables in the Alzheimer's Patient Behavior Checklist were included as dependent variables with Alzheimer's patients' gender as the independent variable for additional analysis of variance. Only two of the twelve variables had significant outcomes, losing things ($F=7.36$, $p<.01$) and talking little or not at all ($F=11.99$, $p<.001$). In addition, the relationship to the caregiver had a significant outcome ($F=17.27$, $p<.001$) and living with the caregiver had a significant outcome (9.89, $p<.01$).

Summary

The quantitative portion of the study allowed this researcher similar information as was collected from the interview process but in a timelier manner. An overall assessment and in-depth information was shared by several of the caregivers who participated in the quantitative portion, however the information was not as detailed as that from the interviewees.

The quantitative portion of the study allowed caregivers to respond to demographic questions, descriptors of the Alzheimer's patient, statements of how the caregiver currently feels, descriptors of trust in the patient's physician, and descriptors of their support system. In addition, caregivers were asked to answer open-ended questions about their experience as a caregiver and changes that had to be made in their life in order to be a caregiver.

There were only two males that participated in the qualitative portion of this study. Similarly, female caregivers were more likely than men to be participants in the quantitative portion. Males were just as likely as females to be the Alzheimer's patient in both the qualitative and quantitative portions.

The majority of the caregivers tended to be 56 to 75 years old while the majority of the patient's were 75 or above. In addition, the majority of caregivers and patients were from a city with a population of more than 50,000 people. Furthermore, the majority of the caregivers did not live with the Alzheimer's patient.

The frequencies provided distributions according to gender or stage of the disease for the variables included in the Alzheimer's Primary Caregivers Questionnaire. Following the frequencies, a factor analysis was conducted and the results coincided with the categories and domains established from the qualitative portion of this study.

Preliminary analysis of variance tests were conducted on several variables with caregiver or patient gender as the independent variable. Patient gender was significant when assessing presence of home modifications. Furthermore, caregiver gender was significant when assessing relationship to patient, patient losing things, and patient talking little or not at all.

Beyond the statistical comparisons, interesting results were provided through the open-ended portion of the quantitative questionnaire. Results from the qualitative interviews included a description of caregivers' strengths and a concept known as meaning-making. Caregivers' strengths and meaning-making also was an important component of the quantitative questionnaire. The last page of the questionnaire allowed caregivers a chance to assess their strengths and many took the opportunity to share in meaning-making through

additional comments written on the back of the questionnaire. Meaning-making in both the quantitative and qualitative portions allowed caregivers to reflect why they believed they were given this challenge, how they hope to help future caregivers, and how they believe the Alzheimer's patient would want to be remembered.

CHAPTER V

DISCUSSION

This discussion will recontextualize the results by adding the researcher's interpretations and connecting salient themes with existing literature about Alzheimer's disease and caregiving. The remaining sections discuss the similarities and uniqueness between past research and this study's outcomes, limitations, and implications. These sections will be presented in the following order:

- Similarities and uniqueness
- Recommendations from caregivers
- Limitations
- Implications
- Clinical implications

Similarities and Uniqueness

The purpose of this study was to learn more about the process involved in living as a primary caregiver of an Alzheimer's patient, and to learn more about the needs of caregivers, the struggles faced, and the satisfactions experienced by caregivers. This information was gathered through ethnographic interviews with twelve primary caregivers of Alzheimer's patients. Qualitative methodologies were used to develop a description of caregivers' experience toward a grounded theory. Quantitative methods were used to confirm results of the interviews and provide data generalizable to similar samples of Alzheimer's caregivers.

Similarities

This study was unique in that it was about understanding the process of caregiving for an Alzheimer's patient. Through in-depth interviews, stages of caregiving were established.

There were similarities among caregivers who cared for an Alzheimer's patient within the same stage. That is, those who cared for someone in the early stages of the disease process tended to share similarities with other caregivers in the same situation. From these interviews, the following caregiver stages were established: early stage, middle stage, late stage, and recently deceased.

Throughout this study Alzheimer's patients described exhibited behaviors such as those detailed in Figure 1. Patients were characterized as having a loss of recent memory, communication difficulties, an inability to perform daily activities, and increased behavior problems. The intensity of these concerns were somewhat dependent upon the stage of the disease process.

These findings are similar to those of Mace and Rabins (1991), which indicated that patients in all three stages of the disease process seem to have difficulties remembering recent events. In addition, those in the early, middle, and late stages tended to mix up past and present and lose personal belongings. However, only those in the middle and late stages had difficulties remembering events that had happened in the past.

Some behaviors were more likely to occur in patients who were in the middle or late stages of the disease than those in the early stages. In this study, wandering was a difficulty for patients in the late stages of the disease. However, patients tend to have difficulties walking as they progress through the last stage. Other behaviors that affect those in middle and late stages are problems recognizing familiar places, restlessness, talking little or not at all, and depression(Gwyther, 1985; Reisberg, Ferris, de Leon, & Crook, 1982). These behaviors coincide with the stages that were detailed in Figure 1. A final behavior that

greatly impacted those in the last stage of the disease was difficulty in starting daily activities such as bathing, dressing, or toileting on their own.

In assessing the needs and struggles of caregivers many similarities between the current study and past research were observed. To begin, past researchers have stated that from a sample of 4,686 caregivers, 76% were female with a mean age of 59, and 67% were the spouse of the patient (Family Caregivers Alliance, 1990-1992). The current study had somewhat different results as 85.7% of the caregivers were female with a mean age between 56 and 65, and 48.6% were the spouse of the patient.

When sharing information about financial assistance, caregivers mentioned the high cost of in-home respite, hospital fees, and nursing home arrangements. The costs in caring for an Alzheimer's patient were a concern for most of the caregivers, especially for the 54.3% that did not currently work. This outcome was similar to results provided by past researchers who have found that 32% of caregivers tend to work in addition to caregiving (Family Caregivers Alliance, 1990-1992). Furthermore, the Family Caregivers Alliance found that an average of 93.3 hours per week was spent caring for the patient. The researcher's results from the current study indicate that approximately 91 hours per week was spent caring for patients. Consequently, an additional occupation seems almost impossible, therefore creating a concern for financial costs incurred during the disease process.

Some of the patients in this study were able to make decisions about their legal needs, others had to rely on their caregivers to make decisions. Caregivers who participated in this study described the patient's lawyers as intelligent and helpful. However, these ratings were low compared to the ratings of other support systems. In fact, lawyers received the lowest marks from caregivers when assessing qualities that caregivers deem important from a

support system. Caregivers felt that necessary documents should be provided to them immediately, including information about guardianship, living wills, and power of attorney. Caregivers from this study would state that their lawyers were helpful, but they didn't know enough about the system.

Seeking medical assistance for the caregiver or for the patient seemed of as much concern to the caregiver as was finding proper legal information. Of utmost concern was the health of the caregiver. Past researchers have found that 43% of caregivers rate their own health as fair to poor (Family Caregivers Alliance, 1990-1992). Similarly, 54.3% of the caregivers who participated in the current study stated that they sometimes or never sleep very well. Furthermore, 62.9% stated that they sometimes or never have lots of energy.

Past literature states that an unfortunate amount of caregivers have been diagnosed with clinically depressive symptoms while caregiving (Family Caregivers Alliance, 1990-1992). Depressive symptoms were also present in many of the caregivers who participated in this study. The majority of caregivers (65.7%) stated that they sometimes or never look forward to things as much as they used to. In addition, 80% feel like crying sometimes or most of the time. Furthermore, 74.3% of caregivers stated that they were lonely sometimes or most of the time.

Caregivers not only had problems with their own mental and physical health, they also had difficulties meeting some of the patient's needs. Caregivers in this study described their embarrassment about problems with incontinence, while others discussed their concern about the patient falling in the home or while wandering. Even worse, some caregivers had seen the patient suffer from pneumonia or another severe illness.

Caregivers had mixed responses when describing the patient's primary physician. Caregivers stated that they thought that the physician cared about the patient but did not consider the physician to be an expert on Alzheimer's. Furthermore, many of the caregivers wished that the doctor had provided them with additional information about how to care for an Alzheimer's patient.

In regard to housing assistance, past researchers have offered several home modifications that may be helpful for both the patient and the caregiver. Safety modifications were added to 54.3% of the patient's home who participated in the current study.. Of those who made adjustments to the patient's home, an average of 2.9 modifications were made to insure safety for the patient. The modifications made to patients' homes surpassed those described in past literature. These modifications included disconnecting the stove, disconnecting water softeners, removing electric blankets, and placing gates near stairways.

Some caregivers were beyond adding modifications to the patients' home. Many caregivers were searching for assisted living or nursing homes. Several statements were made about nursing home staff and assistance, some of which resembled outcomes from the past literature others were unique to the current study.

The statements considered to be unique to this study included statements about the lack of knowledge in nursing home staff and housing providers. Caregivers stated a concern that there isn't enough staff in nursing homes or assisted living facilities and that even if the staff is excellent, they need to be better trained.

Caregivers have a great deal to be concerned with. Consequently, emotional support was a significant topic explored in both the qualitative and quantitative portions of this study.

As mentioned in chapter two, intimacy is rarely assessed in patient/caregiver relationships. This study allowed caregivers the opportunity to express their feelings about their relationships. Spousal caregivers described how difficult it was that their spouse could no longer ask how their day was. They especially mourned the loss of a companion and their togetherness as a couple.

Caregivers of parents were more likely than caregivers for spouses to make positive statements about intimacy during their caregiving experience. Many adult children would comment that caring for their parent brought them closer to that parent. However, the children also stated that they had not anticipated caring for a demented parent.

Caregivers in this study shared a variety of emotions that they have felt throughout their caregiving process. Many of the feelings that caregivers shared have been documented in past research. These emotions included denial, anger, guilt, and depression (Alzheimer's Disease, 1994a).

Caregivers' emotional needs may coincide with the level of emotional support that they receive from practitioners, family members and non-family members. One group of researchers found that 27% of caregivers felt they had no help from family or friends (Family Caregivers Alliance, 1990-1992). Caregivers who participated in the current study provided a mix of outcomes about familial and non-familial support. Caregivers were most likely to describe family members as kind, friendly, and trustworthy. However, 17% of caregivers described family members as hypocritical. On the other hand, caregivers were likely to describe non-family members as kind, friendly, helpful, and easy to get along with. Only 11.4% of the caregivers described non-family members as hypocritical.

Caregivers mentioned services that would be helpful to them and also commented on whose assistance would be most beneficial. Services included help with house work, respite, and assistance for those in rural communities. Many caregivers stated that they would have appreciated more assistance from a particular family member, friend, or the church community. Of the caregivers who participated in this study, 68.6% have attended a support group and 40% take advantage of respite care. Of the 40% who use respite, an average of 18.5 hours per week is utilized for the patient.

Assistance from the church community was a significant topic for many caregivers, even though little research has been done on caregivers and their spirituality. Caregivers described their church community as kind, but were reluctant to use descriptors such as friendly or easy to get along with. In fact, 14.3% of the caregivers described their church community as hypocritical.

Uniqueness

This study was unique because both qualitative and quantitative methodologies were utilized. The publication of qualitative research has been extremely rare. In fact, 99% of the articles that are published in the Journal of Marital and Family Therapy are purely quantitative (Ambert, Adler, Adler, & Detzner, 1995). The qualitative portion of this study included an in-depth exploration into the lives of caregivers. Furthermore, multiple caregivers were able to provide a limited amount of information about caregiving through the quantitative portion of the study.

In contrast to past researchers whose emphasis has traditionally been placed on assessing the negative aspects of caregiving, this study stressed the importance of caregivers having the opportunity to express their strengths and to consider some high points in caring

for an Alzheimer's patient. Caregiver strengths, while difficult to express in a very difficult situation, were significant to include as a part of the study. Caregivers shared strengths such as emotional closeness with the patient, successes experienced while working with the patient, and being able to provide information to other caregivers.

Furthermore, this study included aspects of meaning-making shared by the caregivers who participated in the qualitative portion of the study. Meaning-making included how the caregiver made sense of the disease, how they believed the patient perceived the disease, and how they believed the patient would want to be remembered. Meaning-making was also provided by caregivers who participated in the quantitative portion of the study and shared additional information about the meanings that they considered in relation to difficulties and satisfactions that they had encountered through out the disease process.

Meaning-making included caregivers descriptions of why they think they were given the role of caring for an Alzheimer's patient. Meaning-making was also apparent in statements about what they believed to be the hardest part about caregiving and how they believed the Alzheimer's patient would want to be remembered.

Recommendations From Caregivers

Recommendations to other caregivers and practitioners were offered by several caregivers. Caregivers are the best resource to find out the needs and concerns that pertain to caregiving for an Alzheimer's patient. Caregivers involved in this study recommended that a cleaning service be made available to caregivers that are not able to keep a clean home and care for the patient. Other caregivers wished that lawyers and financial advisors either were knowledgeable in elder affairs or had resources to find such advisors. A number of caregivers made the recommendation that nursing home staff become more knowledgeable

about Alzheimer's. An unfortunate number of the caregivers had to recommend that the church communities become more understanding and interested in the families who are dealing with dementia patients. Finally, many caregivers recommended a service that would take the patient on rides, walks, or away from the home on occasion.

Limitations

One limitation of the qualitative portion of this research project was the cost to conduct such a study. There was a large cost of time devoted to the qualitative portion of the project. Time costs included driving time to each caregiver's home, the time spent with the caregiver during the interview, and additional time spent with the caregiver to conduct member checks and the questionnaire developed for the quantitative portion. In addition, this project was financially costly for both the qualitative and quantitative portions. Financial costs included cost of tapes, discs, copying, postage, and envelopes. Due to the time and financial costs, larger samples were not collected for the study.

A second limitation was that the study was largely cross-sectional. Each caregiver who participated in the qualitative portion was interviewed only once. These caregivers were asked to participate in the quantitative portion no longer than six months after their interview. No significant changes had occurred from the time that the interviewed had occurred. All other caregivers who had participated in the quantitative portion were asked to complete the questionnaire only once. Therefore, a longitudinal study is needed to determine whether the descriptions of caregiver stages theorized in this study are adequate to account for caregivers transitions from one stage to the next. In addition, a longitudinal study is needed to best understand caregivers needs, struggles, satisfactions, and meaning-making over time.

Another limitation was that the study only included those caregivers who were easily assessable to the researcher. While the caregivers who participated in the study had needs, struggles, and satisfactions, there may be caregivers who are isolated and may have different experiences.

Unfortunately no minorities were included in this study. Further studies need to be conducted in areas with larger minority populations. Communities with larger minority populations may yield different results, especially in regard to caregiver needs, struggles, satisfactions, and meaning-making. Minorities must often deal with double or triple jeopardy making situations even more difficult than for those in the Caucasian populations. Double and triple jeopardy refers to discrimination from being at least two of the following: 1) a racial minority, 2) female, 3) over age 65.

Implications

Knowledge of caregivers' needs, struggles, satisfactions, and meaning-making is critical to best understand primary caregivers difficulties and delights. The results of this study may be similar to the experience of other caregivers, especially those who care for someone suffering from a dementia. In addition, caregivers of individuals with AIDS, cancer, Parkinson's, and multiple sclerosis may proceed through stages of caregiving, share stories of meaning-making and certainly deal with needs, and struggles. Future research should be conducted on such illnesses and diseases in order to insure the best care for the patient and the caregiver.

The caregivers who participated in this study expressed how frustrating it was to not receive adequate information from practitioners who are often well respected and perceived as knowledgeable. Practitioners who come into contact with dementia clients or caregivers,

need to have the ability to refer the client to other practitioners who are knowledgeable about the disease process as well as the laws, rules, or care that pertain to the care for a dementia patient. Practitioners need to do what will best help their client. Therefore, general practitioners may need to refer a dementia client or caregiver to a specialist for assistance with specific questions, or to the Alzheimer's Association for general questions and support. Lawyers who help dementia clients or caregivers need to be up-to-date on the governmental policy changes that may affect these individuals. If the lawyer is not knowledgeable about the disease and current laws, he or she needs to refer the client to someone who can best assist with estates, guardianship papers, powers of attorney, living wills, and possibly nursing home placement. In addition, counselors, therapists, and social workers should serve as advocates for the client, as they may be the only non-familial support that the caregiver is receiving.

Aside from practitioners, communities should be aware of families who have a dementia patient in the home. Communities can assist caregivers by having special bracelets placed on patients who tend to wander, provide family restrooms in public areas for patients who have a caregiver of the opposite gender. Communities can also provide an identification for the patient and caregiver that could be shown to individuals who may come into contact with a patient who is unable to respond appropriately to questions (i.e., the grocery store, restaurants, post office).

One implication offered by a support group leader was in response to the questionnaire used in this study. This support group leader mentioned how difficult it was for caregivers to focus on the satisfactions in caregiving or their strengths as a caregiver. This leader mentioned that this topic became the focus of at least one subsequent meeting.

Therefore, not only should the troubling aspects of caregiving be discussed by support groups or adult day center providers, strengths and satisfactions should also be addressed, perhaps as a way of providing hope to others just starting out in the disease process.

Caregivers also offered ideas about how churches can best accommodate dementia patients and families. Caregivers mentioned that pastors and ministers need to be more aware of the struggles that caregivers go through. Church members should also attempt to visit the patient or caregiver, or at least send a card or phone a message letting the family know that they are thought about. Church communities may be the largest group of people who come into contact with a dementia patient or family. These individuals that have the ability to assist caregivers in grocery shopping or providing respite the patient.

Clinical Implications

I believe that caregivers have many more strengths than they realize. Who else could care for a loved one so fully on a daily basis? Primary caregivers dedicate themselves without pay and often times without praise, and they may not realize that they are an inspiration. They are the individuals who took on this full-time job, not by choice but because they were the one who cared. Despite isolation, heart-ache, and loneliness, these caregivers are survivors. Their fight against their struggles may not be over, but by sharing their experience with this researcher, their story will be shared with numerous other caregivers. Through their stories, others can understand how difficult and perhaps satisfying it is to care for someone with Alzheimer's.

Practitioners who work with caregivers and Alzheimer's patients have the ability to encourage caregivers' to explore their needs and struggles. However, caregivers' strengths and meaning-making should also be discussed. Practitioners and support systems who are in

contact with caregivers need to assist caregivers in assessing their strengths. Caregivers are typically overwhelmed with the negative aspects of caregiving, and may find it useful to be reminded of their strengths.

In addition to sharing caregivers' strengths, both caregivers and patients should be encouraged by practitioners to share in meaning-making about their lives and the disease process. Caregivers may find that sharing through meaning-making can serve as a way to validate the difficulties and satisfactions that they encounter through the caregiving process. Alzheimer's patients can also participate in their own meaning-making about their difficulties and satisfactions as they journey through the disease process.

Practitioners should also be aware of the caregivers who reside in rural communities and are not provided the necessary services and assistance available to those in urban communities. Therefore, practitioners need to take an active stance in assisting those in rural homes by providing in-home services.

Furthermore, patients and caregivers should be provided with essential contacts from a physician and therapist at the time of the diagnosis. Physicians and therapists should complete a needs assessment in collaboration with the patient, family, and primary caregiver, in order to organize services. In addition, practitioners should contact agencies that provide assistance. Additional consulting may need to be provided by practitioners to other support systems who are less knowledgeable about the disease process.

The clinical implications just provided are a necessary step toward providing better assistance and services to Alzheimer's caregivers and patients. In addition, patients may be able to stay in their own homes longer if caregivers are given the education and support necessary to care for an Alzheimer's patient. Without additional education and support, the

status for future patients and caregivers is worrisome, especially with the growing population of those over age 65.

Future Research Agenda

Alzheimer's patients represent the majority of individuals cared for in care facilities and adult day centers. With the growing number of individuals approaching the age of 65 and with a dramatic increase in the number of individuals suffering from Alzheimer's, changes are going to have to be made to guarantee safety and appropriate assistance for these individuals. One possibility is to develop an educational program including specific licensure or certification as a dementia specialist for secondary caregivers who work in care facilities, assisted living environments, and adult day centers.

In addition, educational programs need to encourage collaboration from practitioners in multiple disciplines to promote an understanding of the complexities in caring for an Alzheimer's patient and their family. Perhaps a formal registry of gerontologists, physicians, lawyers, therapists, and consultants specialized in elder affairs should be developed for practitioners and caregivers to promote the best care for the patient and family.

APPENDIX A

INFORMED CONSENT STATMENT

The Department of Human Development and Family Studies and the Iowa State University Family Therapy Clinic supports protecting human subjects participating in research studies. The following is provided so that you can decide whether you wish to participate in the present study to be used as a part of a student project and doctoral dissertation. You should be aware that even if you agree to participate, you are free to withdraw at any time.

The purpose of this study is to explore the process of living as an Alzheimer's caregiver. Participation in this study may provide you with a sense that you have contributed to increased understanding as an Alzheimer's caregiver. You may also gain greater insight into others' experiences as a caregiver.

There are no anticipated physical, psychological, social, legal, professional, or economic risks or discomforts. However, the potential exists for discomfort that sometimes accompanies social interaction. This study will request your consent and ask you questions during your involvement in a face to face interview, approximately one to two hours in length .

Your participation in this study is solicited, but strictly voluntary. Please do not hesitate to ask any questions about the study. Confidentiality will be strictly followed and your name will not be associated in any way with the research findings. Your cooperation is greatly appreciated. If you have further questions regarding your participation in this study or you wish to have a copy of the results sent to you at the conclusion of the study, please call Ms. Angela Smith at (515) 268-0232 or Dr. Harvey Joanning at (515) 294-5215.

_____ _____

Signature of the Participant Date

APPENDIX B

PERMISSION TO AUDIOTAPE FORM

Iowa State University Family Therapy Clinic

In order to better understand primary caregivers who have cared for Alzheimer's patients and their needs, struggles, and satisfactions, the focus group and ethnographic interview will be audiotaped and or videotaped.

The audiotapes videotapes will be kept strictly confidential and will be used only with the written permission of the participant.

I give permission to Ms. Angela Smith and the Iowa State Marriage and Family Therapy Clinic to use portions of audiotape and or videotape recording of the ethnographic and or focus group in which I participated. I understand that a condition of this consent is that great care will be taken to maintain the respect and dignity of my opinions and reputation. I also understand that my name will be held confidential. This ethnographic interview may last up to 2 hours.

_____ _____

Signature of Participant Date

APPENDIX C

QUALITATIVE INTERVIEW QUESTIONS

Grand Tour Question

What has it been like for you to be a primary caregiver of an Alzheimer's patient?

Mini Tour Questions

What has it been like living with an Alzheimer's patient?

What has it been like to live as a primary caregiver for an Alzheimer's patient?

Subquestions

Which of your needs do you feel have not been met through your process as a primary

caregiver?

Which of your needs do you feel have been met through your process as a primary caregiver?

Describe any changes in your style of living since becoming a primary caregiver.

Describe any changes in your occupation since becoming a primary caregiver.

What skills or assistance would help you most in your life as a primary caregiver?

Did you experience any differences after the diagnoses in 1) finances, 2) legal matters, 3) medical assistance, 4) housing situation, 5) emotions, 6) spirituality/religion?

APPENDIX D

SAMPLE TRANSCRIPT

Transcript Caregiver # 4

Grand Tour Question

Researcher: I'm interested in learning what it's been like to be a primary caregiver for an Alzheimer's patient?

Caregiver: We lived here with my mother for two years, we moved in with her because we realized something was wrong. And she needed me to be here or she needed to be in a nursing home sooner. We had an idea it was Alzheimer's, we didn't know for sure until we moved in with her. And then she wanted, we wanted her to go to the adult day care center, and to be down there, but she had to have a physical with a neurologist. And he pin-pointed it as probably Alzheimer's, they did a cat scan and said if its 6 or 7 things that show, then we can probably do something about those 6 or 7 things. Alzheimer's won't show up, but he said that if it isn't those 6 or 7, what's left is Alzheimer's.

Researcher: So it's process of elimination, that's how you found out.

Caregiver: Yeah, uh hum.

Researcher: This is your mother?

Caregiver: Uh, she was one of four kids and she went to, there was a convent in * that was closed, they were hoping for a school. And they didn't have enough Catholic kids to go, so they allowed Protestant children to come, so my mother and her sister and one other boy got to got there for two years on scholarship.

Researcher: That's great.

Caregiver: Then she went to * to finish her degree, that's where she met my dad, he was in law school. And then they were married and moved to *, not this house, they moved into this house in 1952, I was in 4th grade. And my mother was a little shorter than I am, I'm about an inch taller than she was, about five feet now with osteoporosis.

Researcher: Right.

Caregiver: And she did a lot of sewing, she didn't work outside the home after she had kids. She worked at Iowa State for five years before I was born, and she made most of her own clothes, because she wasn't very tall and was had to fit. And then she bought for me. I had two brothers, one has died and the other lives in Chicago. Then we moved around a bit and came back here, after my dad died-almost 19 years ago, somehow my mother got very afraid

at night and I knew she wasn't eating much. She was eating maybe a bowl of cereal in the morning and a sandwich and then a sandwich at night, so my husband started picking her up every night on the way home form work and taking her to our home to have supper and then he'd bring her back and she was scared stiff to get out of the car and come in to unlock this backdoor. So one of us would have to come unlock the backdoor and get her in the house and then we'd leave. That was a change, she wasn't like that before. And then, I guess, she'd been there six years, we lived with her two years, so she'd had this probably ten years. We knew things were wrong, we took a great aunt of mine to church one Sunday of each month. And one time we were gone and mother was taking her, 16th Street was closed, you couldn't cross it, and our church is on , so, mother drove by there. There was a gate there, cars could go by, but mother didn't seem to realize it, that cars could get by that gate to get to church or the houses on *. So, my aunt said we drove around for an hour, never did get to church.

Researcher: You realized something was wrong (member check).

Caregiver: So we knew something was wrong there. We knew. And then we moved in with mother 8 years ago, and twice she got out of the house, well after my dad died, she became very afraid. So we had boltlocks put in the front and backdoor. And then we'd keep the key back in the back bathroom right by the backdoor and one in the drawer in the front hallway by the front door. And after we moved in, twice she got out and we had to call the police to find her. The first time was on Thursday, we had always gotten groceries on Thursday, we'd been back here, well 21 years. We moved back here from * when our middle son was born, he's 21 now. And so we'd been in Ames pretty much that long and we'd always gotten groceries on Thursday, and I just had to get out of the house sometimes, she drove me crazy. And so, we went up to Country Kitchen, up north at the time, and had breakfast. And I just said we're going out for awhile, when we come back we'll go get groceries. Well then she, when we came back she was gone. And of course we called the police, I stayed here in case she came back, and my husband went out and the police did. She had walked to the Fareway, the Fareway store downtown.

Researcher: She had wandered away?

Caregiver: And they found her at * and *, so she went south and west to come home. And then, I don't know how the police got way down there to find her, but they did. And then the second time, we didn't take the keys, it didn't dawn on us that she'd do this again. So then the second time, my husband just happened to get up to use the bathroom around 5:00 and saw the front door open. And then she was not in her bedroom, she we again called the police. And I stayed, and he went out, he said that he was amazed with the people that were walking at 5:00 in the morning, but nobody had seen her. And then about a half an hour later the police station called and said they found her and they brought her home, her hands were very bloody. All over, very bloody. And I can't remember if it was this finger or this finger. she, I didn't take her to the hospital right away because it cost money through the emergency room and I knew it wasn't life threatening. But I cleaned her up, and I took her after 8:00, and they had 18 stitches, just in this area of her finger.

Researcher: That must have been scary for all of you.

Caregiver: And she said she was pulling at the door trying to get back in, but she wasn't, She wouldn't have cut her finger on the front door trying to get to do that. So she must have done it on a sharp, needle or something or on a tree or something sharp. But they found her down at 13th, and my husband had been down there a couple of times and he hadn't seen her, just at the end of this block. So, then we decided we'd take the keys away, we still had two kids at home, and we each had one key, bolt lock key with our own keys, and if I was at home the doors were bolted all the time. So she couldn't get out, when my husband's office was downtown, the advertiser building, and I was his secretary for awhile, and somebody, our kids came home. One kid had to be home by 4:00, and the bus brought her back. We took her to the adult daycare center finally because we couldn't stand it, being around her that much. I mean she was my mother, but, and so first she was there two days, then three days, four days and five days. We took her down there in the morning and the bus brought her home. So somebody had to be here for her, to let her in. And then we paid our kids, we had to pay our own kids to stay here. And she couldn't sit still, she wandered around the house, She would follow me around if I went to the bathroom, she would stand outside the bathroom door, if I'd go downstairs, she'd go downstairs. And that's the same thing, my dad's mother had Alzheimer's, they called it senility in those days.

Researcher: Your dad's mother had Alzheimer's (member check).

Caregiver: But my grandma would follow my dad around, she'd be at the bathroom door if Dad was in the bathroom. She'd go to the backdoor when my dad would go to work, we were in school, but I'd see this on the weekends. She came and lived with us after my grandfather died. And my mother, during the week, would say to my grandma come back in here and sit down. And my mother would get her in the living room and sit down, and she'd get up and go back to the door because that's where her son had gone out. And they don't always know who you are, but they know that you are somebody familiar.

Researcher: So you noticed differences in your grandmother and in your mother?

Caregiver: Then she got violent, twice, we have a dishwasher, but every now and then we would not put dishes in the dishwasher. And my husband had left with the two kids, mom was doing the dishes. And she came out twice and hit me in the back, and I hadn't done or said anything. And she had tennis shoes on, so I didn't here her coming. And she hated us, and we would say we love you mom and she would say, well I hate you. And when we were going to move in, we said, this is backing up a little, when we were suggesting we move in - "Oh, I don't need you." Well she did. "I don't need you, I can take care of myself." And she had her anger with the middle son one time, he was still up at 11:00, she apparently realized he was younger than she was and he should be in bed. So she attempted to push him back, to go down the hall to the bedroom, and he put up his hands, and she fell down. He was little, so she didn't get hurt, but I told the kids after that, I said don't get into an argument with her, if she argues with you, just turn around and walk away.

Researcher: Was that part of her personality before the Alzheimer's?

Caregiver: No, she was a nice, loving mother. Never got angry, she was friendly and she was in a sewing group, it's called Thimble Club. It centered around sewing, it started when we were at the old church downtown. Everybody either had no babies or little babies. So it would meet 8:00 to midnight, and the dads would take care of the babies, maybe they got them to bed-the mothers before they left, I don't know. But, she was in a bridge group over the years, toward the end of that, another member of the group was also developing Alzheimer's disease, so one of the ladies said, we sometimes don't play much bridge because, your mom and * are just too mixed up, so they just kind of visit. And they always had coffee and juice.

Researcher: How old was she when you started noticing?

Caregiver: She's 85 now, and I suppose 75, 73.

Caregiver: We knew something was not right. We know she got lost driving, well then, we needed a lawyer to sell the car, because I didn't want her to drive anymore. She would do, you see a lot of older people, when you turn a corner, you go right into the center lane, you're suppose to go into the outside lane. And she'd go to the center lane, because she was going to be turning left on 13th, you see to come home. And I've seen other people do that, mostly older people, but some younger people do it also. And then we wanted to sell her car, and she didn't want to do it. She didn't, "I can still drive." And she was to slow, sometimes when my husband would have the car, so I'd have to go with her, and she'd want to drive because sometimes I 'd make her get out if I would drive, sometimes she would be so slow going down * Avenue twenty-five and your supposed to go thirty-five in the center lane.

Researcher: So, she had some difficulties in her driving (member check).

Caregiver: Then she had car accidents, she ran into the back end of somebody. It wasn't very much damage, she was going the wrong way on a one-way street, and there wasn't very much damage to her car, insurance paid. But, it was right by the police station, and the policemen that responded was * who lived behind us when we lived on *, and he has kids around our older son's age, so he's the only policeman I really now. So when I got the call and I got down there, he said, "I didn't know your mother was still driving." And I said, "We don't want her to, and we can't get her to stop." And he said, "I'll do it for you." When he got there she was LPC, didn't know her first name, couldn't say her last name. She didn't know when her birthday was, she didn't know where she was born, so he said that he would take care of this for us. So he sent this form in to the DOT, about three weeks later, it came back. She was going to have to have a four page medical examination, a written test and a driving test. My mother just said, "I think I won't drive anymore, let's sell the car."

Researcher: You sold the car?

Caregiver: Oh yes, so see she wasn't mad at us then when we wanted her to stop driving.

Researcher: That's a toughie with the driving.

Caregiver: Yes, I hope we won't be so mad about stuff when it's time to stop. Hadn't gone through what my mother did.

Mini-Tour Question

Researcher: So what had this been like for you personally?

Caregiver: Well, it's been hard, and as I said sometimes I just had to get out of the house. Because she hated us, and would tell us that constantly, she hated you, "Why did you have to move in with me?" "I don't like you." And that kind of stuff. And when I was home, I was sometimes, we were in the back bedroom and we left her in the master bedroom, we were in the back bedroom and we changed all of the locks and put key locks on the doors. So that we could get into the bedrooms and lock them and she couldn't get in after us, the boys too. And I'd just go in there and close the door and lock it sometimes, she'd be wandering around, but at least she wasn't after me at the time. And it was stressful, I'm very thankful that they had the daycare, that was a big help. I wish they had it open Saturday and Sunday too.

Researcher: Just on the weekdays then (member check)?

Caregiver: Just on the weekdays. As I said, two days, three days, and then four and then five. So she wasn't in my hair all of the time. And mostly here, she wouldn't sit still, I work for Homeward as a companion of elderly people, and I was with an Alzheimer's patient, she would sit and read the paper, she could read the paper. My mother would hold up a paper and go (ummm) and put it down and then get up and move. She couldn't sit still long enough to read, so I stopped her paper and put it in our name. Stopped her magazines and let her look at the ones I was taking. I changed the address from our house over to here, I let her look at mine, but she wouldn't sit very long and look at them. She'd get up and move around, constantly.

Researcher: Did she seem restless?

Caregiver: We'd always go on picnics on fall days, usually to the park, and mother has worn heels her entire life, well maybe when I was a kid she didn't have heels, well you know, low heels. She had those on one morning, and then she, we were getting ready to go on a picnic and I wanted her to wear tennis shoes, but I'd put tennis shoes on her at 9:00, and she'd go back in and take them off and put on her heels. So, I got smart, I decided I won't put her tennis shoes on until 12:00, load the car with what we are taking for the picnic, go back and put her tennis shoes on and pull her out the door. So she couldn't get anything else on.

Mini-Tour Question

Researcher: What was it like to live with an Alzheimer's patient?

Caregiver: Well, it was stressful. She was just going downhill you know, and she wasn't like she had been, the loving mother, before. Angry with us all of the time, "Why don't you move out?" "Because we sold our house," I'd say. "Find another one," she'd say. But we just stayed here, that's why I'd say sometimes we just had to get out, mostly me, because my husband would be down working. He'd go with me and we'd get out and go walk or something, and bolt the door when we left. So she couldn't get out and follow us.

Researcher: Was she pretty known to wander then?

Caregiver: Well, those two times that she got out, she did. But just around here, she would, oh then, another thing. We had her at the grand Ave. care center, I'm not sure if it has the same name now,up north. They will take short-term patients, and we had her there for about four days, we were going to Chicago to see my brother. We hadn't moved in with her yet, we were trying to decide what to do. And she was just crying and crying, inconsolable, I couldn't stop her. And so I just left and told the staff, I said you'll have to calm her down, I can't do it. And then we went to Chicago and then that, that was like Friday, we were coming back Monday night. We weren't going to pick her up until Tuesday morning, we were going to be back late in the night. And Sunday was the 4th of July, (unintelligible). She got out on a Sunday afternoon, you have to push a button up there and she couldn't reach it, but I think she just followed the Sunday visitors out. And then she started walking North, in the middle of the highway, walking North. We lived south of there, but she was going north, in the middle of the highway. Well, pretty soon a couple found her and decided that maybe this lady came from that nursing home, since she was walking in the middle of the street. The nursing home, when we went to pick her up, didn't tell us, they said she had gone out, but they didn't tell us who had brought her back. And we wanted to call and thank them for doing this. Well then as, my husband has done, when he was a judge he had done legal commitments for people brought into the emergency room. Or brought to the pysch ward, he had to go up and be a lawyer for them, sometimes, not all the time. And he met this psychiatric nurse and she said, "Oh, that was your mother-in-law we picked up."

Caregiver: "six months ago on the 4th of July." He told her thank you, and he said the nursing home didn't tell us who did it. Then as they went back there, the nurse found out and went in and asked if they were missing a patient, and I suppose they said yes. And then Mother say them coming out and she got closer and closer to that husband in the car, she did not want to get out of the car. But then when we took her up there, I asked the doctor who did our blood tests for our wedding and then was our lawyer, our doctor until he retired. And he was Mother's, and I said, "Do we tell her we're taking her up there or do we just go?" He said, "I would just go." And so we did, and I took slacks and some blouses and her own pajamas, and we just walked in the door. That's the hardest thing I have ever done, is to put your parent in a nursing home. And we took her back, this care facility has the east wing which is called mobile confused, most people have Alzheimer's, but some are, some other form of dementia. And so that was the hardest thing I've ever done, put her in there.

Researcher: How did you decide that was what needed to be done?

Caregiver: Because we just couldn't take it anymore. I think they called, we had applied there. Well actually we had applied at * Avenue too, I took her name off because they don't have a concealed unit for people there. I took her name off there and then I had it at *, and they called at 3 months and we didn't need it, at three months her name goes to the bottom of the list. By the time we needed it, I, by the time they called back, then I needed it. It was sad. And that's what they say, it's stressful for, it's not stressful for them because they, because they don't know what's wrong. It's stressful for the people that live with them.

Sub-Question

Researcher: What needs of yours do you feel were not really adequately met through the care giving process?

Caregiver: Well, I don't really think that I had many because, as I said it was about a month or two months after we moved in that we got her down to the daycare center. So that was a big help. And a couple of times I went to the support group at our church. But, at the time there were three other women there, it was all husbands that were, who had it. And nobody had a mother, and then as soon as she got to the care facility, then we started going to a support group every month for six years. I think we've missed two, or something.

Researcher: And how have those been helpful for you?

Caregiver: That's helpful because, even though most, well we've got some new people now, people in there in the east wing. Some of the old ones are still there and they were wise of these men, but still we knew what the men were going through because my husband and I had gone through it. And now there's a, there are two couples that come, and they're, I think it's a brother and sister and their spouses. One of them was there that night, the other was-I can't remember, and that mother is in there now. So I think that's the first time there has been a mother there, somebody that has a mother.

Researcher: That was the first time that there was a caregiver who cared for a mother (member check)?

Caregiver: They used to say that the more education you had, the less chance you had to get this. But mother had a college degree, and I don't know what she had, maybe a masters. One guy was a minister, he would be, at Christmas time, would have a Christmas party, and then he would get up and give a prayer and everybody just kind of held their breath. To see what he would say, but he did allright. He did it, he did it alright. And he's still there. I think he's, he's in a wheelchair now, I guess he's not what he used to be. When you can't walk anymore, and so she's in a wheelchair. She hasn't known me for several years, probably about three years ago I said, I said, "I love you mother, do you know who I am?" And you're not supposed to ask these people do you know who I am? But three years ago I did, and I could see her thinking, she said, "Well, you're a very nice lady." But, she couldn't come up

with my name. And now she can't talk at all, she mumbles and kind of whispers, but you can't tell what she's saying. But it has nothing to do, if we ask her a question, she can't answer it, she mumbles.

Researcher: Other than having someone to relate to, how have your support groups been helpful to you?

Caregiver: Well, I think just because we go every month and meet with these people, sometimes some of us will cry, depending on what's being said.

Researcher: So it is really hard sometimes.

Caregiver: This horrible, and I've said, "I would not wish this on the worst enemy, I don't have enemies, and if I did, I would not wish this on them anyway." And I hope I don't get it, you see, her sister in the Philippines had it, she died about four weeks ago. She also had osteoporosis.
I think they got to where they just couldn't feed her, so she died. And I didn't even tell my mom, I don't think she'd understand anyway. I had a brother that died a year ago at Easter, and I didn't tell her that, because, again, I don't think she'd understand and she'd, I don't want to take the chance that she would understand. And they've called this the long goodbye and the never-ending funeral, and about a year ago, I think it was 8 months, they called and said she had rails in her lungs. I thought that meant pneumonia, and I thought that was the end, see we've decided not to give her a flu shot or pneumonia shot, if she get it then that's the end. We're just trying to keep her comfortable, and so I thought she had pneumonia, and so I thought that was the end. And then I was going up everyday and I wasn't working yet, I was between jobs, and so, usually if I'm between jobs. I have maybe a week off, two, before they get me to somebody else. So I was going over everyday and finally, about the third time I said, " Well, how is the pneumonia"? They said it isn't pneumonia, it's congestive heart failure.

Researcher: It was congestive heart failure?

Caregiver: That fills up the lungs, and sometimes her hands are very blue. And sometimes her feet are swollen, Sunday-we just go up on Sundays now, her feet were swollen and that's due to the congestive heart failure. And they're not treating that, but somebody said she could live 8-15 years with that. Because she's already lost as a mother, and she could still smile, people will say, "Oh, I think she knew me, she smiled." Well, she smiles but she doesn't know anybody. But that is one thing she can still do is smile. Well, as I said, her sister had it, on my dad's side my grandmother was senile, first cousin of my dad's had it.

Researcher: What kind of support did you get from your siblings?

Caregiver: None.

Researcher: Really?

Caregiver: I was kind of angry about that. And one time, my brother said, that I said that she doesn't know me, but I still go up there to see her. She is still my mother even if she doesn't know me. And one time my brother * was here, he had some mental problems, and he and his wacky girlfriend were here. And they were screaming and yelling at my mother up there to get her to sign this thing to get them $10,000. And it just happened that the doctor still made calls to mother and four or five other people up there, patients, and so he would go up there about every 4 months to see them. And he and *'s dad were walking in to mother's, to see her, at the time my brother was yelling at her, trying to get this money. She wasn't understanding what they were saying, and then I said to the nurses, if he comes back here anymore, he is not allowed to take my mother out. He wanted to get her outside, to put pressure on her, they thought, outside the building. So I said, well, if he comes back again, I said don't let him take her out. And I also said have somebody in the room so that this doesn't happen again. And then my other brother said that if she doesn't know me, if she doesn't know you-he said, then why should I come? So, they never did. That's again, my support was the daycare. We just had evenings and Saturday and Sunday. And we get, well we don't take it right now, but we had the Lutheran magazine, and Minneapolis has seven-day daycare. And I think that they were going to try it here, but not enough people wanted it.

One time we were taking her to church, and one time we got back from communion, somehow she got back to her seat before we did, and we were in this row and she was back here in the middle of this row, people must have thought what is that lady coming in here for? That row hadn't gone up yet. So, she crawled across I don't know how many people and go to the center, she wasn't in our row, I think that was the last time we took her to church. It wasn't very long after that that she went to the nursing home, I think they called after that, they called on a Thursday to say that they were coming to talk to us on a Friday, and they did. And then they called back later Friday and said bring her Monday. That fast.

Sub-Question

Researcher: Have you have been satisfied with medical information that you have received about Alzheimer's?

Caregiver: Oh yeah. From the Alzheimer's association. We got a lot of stuff from them. We needed things, things for teenagers, because we still had two kids at home.

Researcher: You needed books about Alzheimer's for your children?

Caregiver: I got stuff for them to read, and it helped to read what other people had gone through. We got some brochures from other people whose family were now in a nursing home. What they had gone through, so we sort of had an idea of what this might, but you see everybody is different. Nobody is the same, we thought well, maybe this will happen, or this will happen, and it did.

Sub-Question

Researcher: How were you treated by doctors, information form doctors themselves?

Caregiver: Fine, I think okay. When she saw this neurologist, one of the questions he asked was, who's president, and I think it was Bush at the time, and she said Roosevelt. And he said good choice, wrong name this time, but good choice. And then he said, what did you have for lunch? It was around 2:00, and he asked what she had for lunch and she couldn't say. She said something, oh she said we had hamburgers on the grill, and we had peanut butter, I had it on toast and I think she had it on bread, and we had fruit. And she said we had hamburgers on the grill. No, we didn't. I think he asked her to count backwards and she couldn't do that. And I'm not sure if she could even count forwards. I know he asked her to count backwards. And he told me things to expect. And then her doctor, he had some other people who had, he was in internal medicine, he had some other people that had Alzheimer's. He was a help.

Researcher: Who made her medical arrangements for her? Things that had to be signed at the nursing home.

Caregiver: I put my name on her checks after I moved in, because she was, I found, we used to have our garbage cans outside, and I found bills in the garbage can, and I didn't know what she was doing with the checks, so I got my name on, and I wrote, any checks she needed, I wrote. And then I have power of attorney, when she was living here, I still do. And as I have said, I have talked with her doctor and my brother, and that's why were not giving the flu shot.

Sub-Question

Researcher: Has being a caregiver effected you financially?

Caregiver: My father was a lawyer. He had plenty of money. There was a family trust in the * Agency and when she gets her social security check each month it goes into the agency at the bank, and the bank pays the nursing home bill.

Caregiver: All I pay is the pharmacy.

Sub-Question

Researcher: Are there things that would have helped you get through this easier?

Caregiver: Not really, except for the fact that my brothers would never come. Or they'd tell us they would come relieve us so that we could go off for a week, but they never did.

Researcher: So more family support would have made this easier? Are there other things that would have helped you?

Caregiver: I don't think so, because as I said, it wasn't very long before we had that daycare and that was a tremendous help. And then sometimes we would just have to get out at night, and we'd pay the kids to stay with her. It was like having a child, you'd pay for a baby-sitter for a kid. We paid the kids to stay with Grandma.

Sub-Question

Researcher: Are there skills or certain kinds of assistance that you wish you would have had through this?

Caregiver: don't think so because we got a lot of stuff from the Alzheimer's association.

Sub-Question

Researcher: Did you feel like your style of living changed?

Caregiver: Well, I suppose, just because we had to lock the doors, as I said I put all of her clothes in the cedar closet and locked it. That was a change, and there was a button at the top of the basement door here and we kept that locked, after she came up in the dirty underwear. So she couldn't go down there, I also thought she could fall. Fall down the stairs, and we locked that so she couldn't go down there.

Sub-Question

Researcher: Were there housing modifications that had to be made other than adding locks to the doors.

Caregiver: We had taken away the knobs on the oven, and the sharp knives. Because she threatened to kill herself several times. So, then when I was cooking, I'd have somebody out in the kitchen all of the time, if I had to go to the bathroom, or down to the laundry. I'd have one of the kids out here because she was out here, I wouldn't want her to do something on the stove. So I would have to have a kid out here.

Sub-Question

Researcher: How does religion fit into your lives, your beliefs or spirituality, your mother's beliefs?

Caregiver: Well as I say, that helps. And I think she'll still go to heaven despite her hates, hating us. She was not like this early on, that was not her. And as I say, we go to church every Sunday, for as long as I can remember and still do. So, I think that helps. The visitation pastor, he came to see mother and get her communion.

Sub-Question

Researcher: Are there things that haven't been helpful for you?

Caregiver: I don't really think so. Because we knew the director of the Alzheimer's Association and she would sometimes bring things over. You know, videos we could watch.

Sub-Question

Researcher: What did you find that was helpful?

Caregiver: Once in awhile if we were all gone, there are a couple of friends that would come and stay with her, if we were all gone for the evening or something. There are two sets of friends that came, I think twice and stayed with her. And one time we went on a trip, I think we were gone two weeks, we used Homeward. I don't know why she cried so much when we took her up to the nursing home, because she was here those two weeks when we were gone, and I don't know why she cried when we put her up there.

Additional Questions

Researcher: If there was one thing that you could tell the other caregivers, what would that be?

Caregiver: Expect anything, to happen because as I say, everybody is different, so you don't know how anybody is going to get through this. As I said, my grandma was quiet, she didn't say anything. Grandma didn't hit anybody, and Mom did. And Grandma wandered and so did my mom, but I don't think Grandma ever got out, I never heard my parents say that she got away. As I said, everybody's different.

Researcher: Did you talk with your children quite a bit about what Alzheimer's was?

Caregiver: They knew, they didn't know my grandparents, my grandma of course, she died when I was 12. And the last time my aunt was here, well they saw her, she was in the Alzheimer's yet so the kids didn't see this aunt in Alzheimer's. But they knew what to expect, they lived it, it was two years. My oldest was a junior, he had two years here and my youngest was in 8th grade I guess. No, he was, my oldest was younger than that, they were three years apart, my youngest boy was in 6th grade and my oldest boy was in 10th grade. So they, we talked to them about it, what to expect and they heard her telling us that she hated us. And they could see her wander on weekends, she was always wandering around.

Researcher: Do you think that affected your family as a whole?

Caregiver: I don't think so, really very much. The kids were gone all day and that helped them. And we, when I started working for my husband, that's when we had her in the daycare center. It was stressful, but that's why we had to sometimes just get out. We'd go for

a walk or go to a movie, and that morning when we went up to Country Kitchen and she got out, that day. I don't know why we didn't take the keys away the first time she did that, so then the second time she wandered-oh we're going to take the keys away. You just learn this stuff by trial and error.

Researcher: If you were to ask your mother how she would want to be remembered, what do you think her response would be?

Caregiver: I suppose a loving mother, she loved the kids. She loved us, told us she loved us as kids, and would hug us, help us with homework if we needed it.

APPENDIX E

INFORMED CONSENT STATEMENT

The Department of Human Development and Family Studies and the Iowa State University Family Therapy Clinic supports protecting human subjects participating in research studies. The following is provided so that you can decide whether you wish to participate in the present study to be used as a part of a student project and doctoral dissertation. You should be aware that even if you agree to participate, you are free to withdraw at any time.

The purpose of this study is to explore the process of living as an Alzheimer's caregiver. Participation in this study may provide you with a sense that you have contributed to increased understanding as an Alzheimer's caregiver. You may also gain greater insight into others' experiences as a caregiver.

There are no anticipated physical, psychological, social, legal, professional, or economic risks or discomforts. However, the potential exists for discomfort that sometimes accompanies social interaction. This study will request your consent and ask you questions during your involvement in a close and open-ended questionnaire.

Your participation in this study is solicited, but strictly voluntary. Please do not hesitate to ask any questions about the study. Confidentiality will be strictly followed and your name will not be associated in any way with the research findings. Your cooperation is greatly appreciated. If you have further questions regarding your participation in this study or you wish to have a copy of the results sent to you at the conclusion of the study, please call Ms. Angela Smith at (515) 268-0232 or Dr. Harvey Joanning at (515) 294-5215.

_____ _____

Signature of the Participant Date

APPENDIX F

ALZHEIMER'S PRIMARY CAREGIVERS QUESTIONNAIRE

Please place a check next to the category that best reflects your age:

___under 20 ____20-35 ____36-45 ____46-55 ___56-65 ___65-75
___75+

Please place a check next to the category that best reflects the age of the individual with Alzheimer's that you care for:

___under 20 ____20-35 ____36-45 ____46-55 ___56-65 ___65-75
___75+

What is your gender:
____male
____female

What is the gender of the individual with Alzheimer's that you care for:
____male
____female

Place a check next to the category that best reflects your educational attainment:
___less than high school ____high school ____some/2yrs of college
___4 years of college ____Master's degree ____Ph.D.

Place a check next to the category that best reflects the educational attainment of the individual with Alzheimer's:
___less than high school ____high school ____some/2yrs of college
___4 years of college ____Master's degree ____Ph.D.

Do you live with the individual with Alzheimer's that you care for:
____yes
____no

Please place a check next to the category that best describes the care-receiver's relation to you:
____spouse ____father ____mother ____brother ____sister ____neighbor
____daughter ____son other_____

Approximately how many hours do you spend caring for the individual with Alzheimer's on any given day:
____1-5hours ____6-10hours ____11-15hours _____16-20hours ____21-24hours

The following questions allow you, the caregiver to describe the individual that you are caring for (the individual with Alzheimer's Disease). Please consider if any of the following situations have occurred during the past week. If so, how often have they occurred? If not, has this problem ever occurred?

Frequency Ratings

0= Never Occurred
1= Occurred frequently in the past but not in the past three months
2= Has occurred recently, but not in the past week
3= Has occurred 1or 2 times in the past week
4= Has occurred 3 to 6 times in the past week
5= Occurs daily or more often
6= This problem would occur, if the patient wasn't supervised

**Please circle the frequency that best fits the behavior of the individual with Alzheimer's **

Behavior	Frequency						
1. Trouble remembering recent events	0	1	2	3	4	5	6
2. Trouble remembering significant events from past	0	1	2	3	4	5	6
3. Mixing up past and present	0	1	2	3	4	5	6
4. Losing or misplacing things	0	1	2	3	4	5	6
5. Wandering or getting lost	0	1	2	3	4	5	6
6. Not recognizing a familiar place	0	1	2	3	4	5	6
7. Unable to start daily activities by self (bath, dress, eat)	0	1	2	3	4	5	6
8. Being constantly restless/agitated	0	1	2	3	4	5	6
9. Talking little or not at all	0	1	2	3	4	5	6
10. Being suspicious or accusative	0	1	2	3	4	5	6
11. Appears sad or depressed	0	1	2	3	4	5	6
12. Strikes out or tries to hit	0	1	2	3	4	5	6

Please answer as honestly as you can the number that best refers to how you felt over the past week.

1= Most of the time
2= Sometimes
3= Never

_____ 1. I look forward to things as much as I used to
_____ 2. I sleep very well
_____ 3. I feel like crying
_____ 4. I feel like running away
_____ 5. I have lots of energy
_____ 6. I feel very lonely
_____ 7. I feel very bored

Each item below is a statement with which you may agree or disagree. Beside each statement is a scale that ranges from strongly agree (1) to strongly disagree (5). For each item please circle the number that represents the extent to which you agree or disagree with the statement.

1= Strongly Agree
2= Agree
3= Neutral
4= Disagree
5= Strongly disagree

1. I doubt that the doctor really cares about me as a person.	1	2	3	4	5
2. I doubt that the doctor cares for the care-receiver as a person.	1	2	3	4	5
3. If the doctor tells me something, it must be true.	1	2	3	4	5
4. I feel the doctor does not do everything he/she could for the individual with Alzheimer's that I care for.	1	2	3	4	5
5. The doctor that the Alzheimer's patient visits is an expert in taking care of Alzheimer's patients.	1	2	3	4	5
6. The doctor gives me the information I need to know about caring for someone with Alzheimer's Disease.	1	2	3	4	5
7. I sometimes distrust the doctor's opinion and would like a second opinion.	1	2	3	4	5

Listed below are a number of words that can be used to describe people. In the space provided, place a check next to the words that describe the individual listed at the top of each column.

Doctor that the Alzheimer's Patient has seen throughout disease process	**Familial Support System**	**Non-Familial Support System (Neighbors/Support Group)**
____1. Kind	____1. Kind	____1. Kind
____2. Hypocritical	____2. Hypocritical	____2. Hypocritical
____3. Friendly	____3. Friendly	____3. Friendly
____4. Trustworthy	____4. Trustworthy	____4. Trustworthy
____5. Wise	____5. Wise	____5. Wise
____6. Phony	____6. Phony	____6. Phony
____7. Intelligent	____7. Intelligent	____7. Intelligent
____8. Ethical	____8. Ethical	____8. Ethical
____9. Competent	____9. Competent	____9. Competent
____10. Knowledgeable	____10. Knowledgeable	____10. Knowledgeable
____11. Dishonest	____11. Dishonest	____11. Dishonest
____12. Likable	____12. Likable	____12. Likable
____13. Helpful	____13. Helpful	____13. Helpful
____14. Loving	____14. Loving	____14. Loving
____15. Easy to get along with	____15. Easy to get along with	____15. Easy to get along with

Listed below are a number of words that can be used to describe people. In the space provided, place a check next to the words that describe the individual listed at the top of each column.

Lawyer/ legal consultant	**Church Community**	**Alzheimer's Patient (current condition)**
____1. Kind	____1. Kind	____1. Kind
____2. Hypocritical	____2. Hypocritical	____2. Hypocritical
____3. Friendly	____3. Friendly	____3. Friendly
____4. Trustworthy	____4. Trustworthy	____4. Trustworthy
____5. Wise	____5. Wise	____5. Wise
____6. Phony	____6. Phony	____6. Phony
____7. Intelligent	____7. Intelligent	____7. Intelligent
____8. Ethical	____8. Ethical	____8. Ethical
____9. Competent	____9. Competent	____9. Competent
____10. Knowledgeable	____10. Knowledgeable	____10. Knowledgeable
____11. Dishonest	____11. Dishonest	____11. Dishonest
____12. Likable	____12. Likable	____12. Likable
____13. Helpful	____13. Helpful	____13. Helpful
____14. Loving	____14. Loving	____14. Loving
____15. Easy to get along with	____15. Easy to get along with	____15. Easy to get along with

Please take a few moments to respond to the following open-ended questions:

1. Do you have a job in addition to caring for the individual with Alzheimer's?
   ____yes ____no
   ** If yes, how many hours do you work?_____

2. Do you participate in support groups for Alzheimer's caregivers?
   ____yes ____no

3. Do you take advantage of respite options?
   ____yes ____no
   **If yes, how many hours per week do you use respite?_____

4. Please list any areas that you wish you had more help with:

_____

_____

5. Please state any modifications that needed to be made to the home where the individual with Alzheimer's currently resides, because of safety reasons for that individual.

_____

_____

_____

6. Please list any suggestions that may have made this process (caring for an individual with Alzheimer's) easier on you.

_____

_____

_____

7. If you were to guess what stage the individual that you are caring for is currently in what would you say?
   _____early stages of Alzheimer's _____middle stages of Alzheimer's
   _____late stages of Alzheimer's

8. Please state some strengths, happy times, or satisfactions in caring for an Alzheimer's patient._____

_____

_____

9. Please state any additional comments that you would like to add to better help me understand the needs, struggles, and satisfactions in caring for an Alzheimer's patient.

_____

_____

_____

APPENDIX G

ADDITIONAL RESULTS

Evaluation of Social Support Checklist

doctor kind

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	5	14.3	14.3	14.3
	present	30	85.7	85.7	100.0
	Total	35	100.0	100.0	

doctor hypocritical

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	34	97.1	97.1	97.1
	present	1	2.9	2.9	100.0
	Total	35	100.0	100.0	

doctor friendly

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	4	11.4	11.4	11.4
	present	31	88.6	88.6	100.0
	Total	35	100.0	100.0	

doctor trustworthy

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	12	34.3	34.3	34.3
	present	23	65.7	65.7	100.0
	Total	35	100.0	100.0	

doctor wise

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	23	65.7	65.7	65.7
	present	12	34.3	34.3	100.0
	Total	35	100.0	100.0	

doctor phony

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	35	100.0	100.0	100.

doctor intelligent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	9	25.7	25.7	25.7
	present	26	74.3	74.3	100.0
	Total	35	100.0	100.0	

doctor ethical

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	14	40.0	40.0	40.0
	present	21	60.0	60.0	100.0
	Total	35	100.0	100.0	

doctor competent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	11	31.4	31.4	31.4
	present	24	68.6	68.6	100.0
	Total	35	100.0	100.0	

doctor knowledgeable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	13	37.1	37.1	37.1
	present	22	62.9	62.9	100.0
	Total	35	100.0	100.0	

doctor dishonest

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	35	100.0	100.0	100.

doctor likable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	9	25.7	25.7	25.7
	present	26	74.3	74.3	100.0
	Total	35	100.0	100.0	

doctor helpful

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	8	22.9	22.9	22.9
	present	27	77.1	77.1	100.0
	Total	35	100.0	100.0	

doctor loving

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	25	71.4	71.4	71.4
	present	10	28.6	28.6	100.0
	Total	35	100.0	100.0	

doctor easy get along with

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	10	28.6	28.6	28.6
	present	25	71.4	71.4	100.0
	Total	35	100.0	100.0	

family kind

		Frequency	Percent	Valid Percent	.Cumulative Percent
Valid	not present	6	17.1	17.1	17.1
	present	29	82.9	82.9	100.0
	Total	35	100.0	100.0	

family hypocritical

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	29	82.9	82.9	82.9
	present	6	17.1	17.1	100.0
	Total	35	100.0	100.0	

family friendly

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	9	25.7	25.7	25.7
	present	26	74.3	74.3	100.0
	Total	35	100.0	100.0	

family trustworthy

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	8	22.9	22.9	22.9
	present	27	77.1	77.1	100.0
	Total	35	100.0	100.0	

family wise

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	21	60.0	60.0	60.0
	present	14	40.0	40.0	100.0
	Total	35	100.0	100.0	

family phony

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	33	94.3	94.3	94.3
	present	2	5.7	5.7	100.0
	Total	35	100.0	100.0	

family intelligent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	11	31.4	31.4	31.4
	present	24	68.6	68.6	100.0
	Total	35	100.0	100.0	

family ethical

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	17	48.6	48.6	48.6
	present	18	51.4	51.4	100.0
	Total	35	100.0	100.0	

family competent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	17	48.6	48.6	48.6
	present	18	51.4	51.4	100.0
	Total	35	100.0	100.0	

family knowledgeable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	18	51.4	51.4	51.4
	present	17	48.6	48.6	100.0
	Total	35	100.0	100.0	

family dishonest

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	35	100.0	100.0	100.

family likable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	12	34.3	34.3	34.3
	present	23	65.7	65.7	100.0
	Total	35	100.0	100.0	

family helpful

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	11	31.4	31.4	31.4
	present	24	68.6	68.6	100.0
	Total	35	100.0	100.0	

family loving

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	11	31.4	31.4	31.4
	present	24	68.6	68.6	100.0
	Total	35	100.0	100.0	

family easy get along with

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	9	25.7	25.7	25.7
	present	26	74.3	74.3	100.0
	Total	35	100.0	100.0	

non-family kind

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	5	14.3	14.3	14.3
	present	30	85.7	85.7	100.0
	Total	35	100.0	100.0	

non-family hypocritical

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	31	88.6	88.6	88.6
	present	4	11.4	11.4	100.0
	Total	35	100.0	100.0	

non-family friendly

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	4	11.4	11.4	11.4
	present	31	88.6	88.6	100.0
	Total	35	100.0	100.0	

non-family trustworthy

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	13	37.1	37.1	37.1
	present	22	62.9	62.9	100.0
	Total	35	100.0	100.0	

non-family wise

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	19	54.3	54.3	54.3
	present	16	45.7	45.7	100.0
	Total	35	100.0	100.0	

non-family phony

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	33	94.3	94.3	94.3
	present	2	5.7	5.7	100.0
	Total	35	100.0	100.0	

non-family intelligent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	14	40.0	40.0	40.0
	present	21	60.0	60.0	100.0
	Total	35	100.0	100.0	

non-family ethical

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	15	42.9	42.9	42.9
	present	20	57.1	57.1	100.0
	Total	35	100.0	100.0	

non-family competent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	15	42.9	42.9	42.9
	present	20	57.1	57.1	100.0
	Total	35	100.0	100.0	

non-family knowledgeable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	11	31.4	31.4	31.4
	present	24	68.6	68.6	100.0
	Total	35	100.0	100.0	

non-family dishonest

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	34	97.1	97.1	97.1
	present	1	2.9	2.9	100.0
	Total	35	100.0	100.0	

non-family likable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	9	25.7	25.7	25.7
	present	26	74.3	74.3	100.0
	Total	35	100.0	100.0	

non-family helpful

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	7	20.0	20.0	20.0
	present	28	80.0	80.0	100.0
	Total	35	100.0	100.0	

non-family loving

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	14	40.0	40.0	40.0
	present	21	60.0	60.0	100.0
	Total	35	100.0	100.0	

non-family easy get along with

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	7	20.0	20.0	20.0
	present	28	80.0	80.0	100.0
	Total	35	100.0	100.0	

lawyer kind

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	20	57.1	57.1	57.1
	present	15	42.9	42.9	100.0
	Total	35	100.0	100.0	

lawyer hypocritical

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	34	97.1	97.1	97.1
	present	1	2.9	2.9	100.0
	Total	35	100.0	100.0	

lawyer friendly

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	18	51.4	51.4	51.4
	present	17	48.6	48.6	100.0
	Total	35	100.0	100.0	

lawyer trustworthy

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	19	54.3	54.3	54.3
	present	16	45.7	45.7	100.0
	Total	35	100.0	100.0	

lawyer wise

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	24	68.6	68.6	68.6
	present	11	31.4	31.4	100.0
	Total	35	100.0	100.0	

lawyer phony

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	34	97.1	97.1	97.1
	present	1	2.9	2.9	100.0
	Total	35	100.0	100.0	

lawyer intelligent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	15	42.9	42.9	42.9
	present	20	57.1	57.1	100.0
	Total	35	100.0	100.0	

lawyer ethical

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	19	54.3	54.3	54.3
	present	16	45.7	45.7	100.0
	Total	35	100.0	100.0	

lawyer competent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	19	54.3	54.3	54.3
	present	16	45.7	45.7	100.0
	Total	35	100.0	100.0	

lawyer knowledgeable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	17	48.6	48.6	48.6
	present	18	51.4	51.4	100.0
	Total	35	100.0	100.0	

lawyer dishonest

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	34	97.1	97.1	97.1
	present	1	2.9	2.9	100.0
	Total	35	100.0	100.0	

lawyer likable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	24	68.6	68.6	68.6
	present	11	31.4	31.4	100.0
	Total	35	100.0	100.0	

lawyer helpful

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	15	42.9	42.9	42.9
	present	20	57.1	57.1	100.0
	Total	35	100.0	100.0	

lawyer loving

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	32	91.4	91.4	91.4
	present	3	8.6	8.6	100.0
	Total	35	100.0	100.0	

lawyer easy get along with

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	26	74.3	74.3	74.3
	present	9	25.7	25.7	100.0
	Total	35	100.0	100.0	

church kind

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	12	34.3	34.3	34.3
	present	23	65.7	65.7	100.0
	Total	35	100.0	100.0	

church hypocritical

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	30	85.7	85.7	85.7
	present	5	14.3	14.3	100.0
	Total	35	100.0	100.0	

church friendly

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	14	40.0	40.0	40.0
	present	21	60.0	60.0	100.0
	Total	35	100.0	100.0	

church trustworthy

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	20	57.1	57.1	57.1
	present	15	42.9	42.9	100.0
	Total	35	100.0	100.0	

church wise

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	26	74.3	74.3	74.3
	present	9	25.7	25.7	100.0
	Total	35	100.0	100.0	

church phony

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	33	94.3	94.3	94.3
	present	2	5.7	5.7	100.0
	Total	35	100.0	100.0	

church intelligent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	25	71.4	71.4	71.4
	present	10	28.6	28.6	100.0
	Total	35	100.0	100.0	

church ethical

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	20	57.1	57.1	57.1
	present	15	42.9	42.9	100.0
	Total	35	100.0	100.0	

church competent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	20	57.1	57.1	57.1
	present	15	42.9	42.9	100.0
	Total	35	100.0	100.0	

church knowledgeable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	24	68.6	68.6	68.6
	present	11	31.4	31.4	100.0
	Total	35	100.0	100.0	

church dishonest

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	34	97.1	97.1	97.1
	present	1	2.9	2.9	100.0
	Total	35	100.0	100.0	

church likable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	16	45.7	45.7	45.7
	present	19	54.3	54.3	100.0
	Total	35	100.0	100.0	

church helpful

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	18	51.4	51.4	51.4
	present	17	48.6	48.6	100.0
	Total	35	100.0	100.0	

church loving

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	20	57.1	57.1	57.1
	present	15	42.9	42.9	100.0
	Total	35	100.0	100.0	

church easy get along with

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	16	45.7	45.7	45.7
	present	19	54.3	54.3	100.0
	Total	35	100.0	100.0	

patient kind

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	11	31.4	31.4	31.4
	present	24	68.6	68.6	100.0
	Total	35	100.0	100.0	

patient hypocritical

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	33	94.3	94.3	94.3
	present	2	5.7	5.7	100.0
	Total	35	100.0	100.0	

patient friendly

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	12	34.3	34.3	34.3
	present	23	65.7	65.7	100.0
	Total	35	100.0	100.0	

patient trustworthy

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	26	74.3	74.3	74.3
	present	9	25.7	25.7	100.0
	Total	35	100.0	100.0	

patient wise

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	32	91.4	91.4	91.4
	present	3	8.6	8.6	100.0
	Total	35	100.0	100.0	

patient phony

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	34	97.1	97.1	97.1
	present	1	2.9	2.9	100.0
	Total	35	100.0	100.0	

patient intelligent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	31	88.6	88.6	88.6
	present	4	11.4	11.4	100.0
	Total	35	100.0	100.0	

patient ethical

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	27	77.1	77.1	77.1
	present	8	22.9	22.9	100.0
	Total	35	100.0	100.0	

patient competent

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	33	94.3	94.3	94.3
	present	2	5.7	5.7	100.0
	Total	35	100.0	100.0	

patient knowledgeable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	33	94.3	94.3	94.3
	present	2	5.7	5.7	100.0
	Total	35	100.0	100.0	

patient dishonest

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	35	100.0	100.0	100.

patient likable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	13	37.1	37.1	37.1
	present	22	62.9	62.9	100.0
	Total	35	100.0	100.0	

patient helpful

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	21	60.0	60.0	60.0
	present	14	40.0	40.0	100.0
	Total	35	100.0	100.0	

patient loving

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	11	31.4	31.4	31.4
	present	24	68.6	68.6	100.0
	Total	35	100.0	100.0	

patient easy get along with

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not present	18	51.4	51.4	51.4
	present	17	48.6	48.6	100.0
	Total	35	100.0	100.0	

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